



The COFAR VOICE

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DMR Waiver Changes Aid Home Caregivers (page 4); Child Autism (page 5)



DMR Commissioner Elin Howe met with the COFAR board of directors and members October 2 at the Glavin Center in Shrewsbury. Full story on page 4. (Photo by Mark Zanger)

Advocacy Keeps On Working

Cases tracked by COFAR show that sustained advocacy by family members and guardians wins real improvements for our loved ones. "The courts also have been upholding the rights of our loved ones not be moved around to suit the convenience of the system," adds COFAR President David J. Hart. "But we are still seeing the hostility toward persistent advocates, which seems to be a characteristic of an overwhelmed bureaucracy that doesn't really regulate itself or its contractors," Hart added. "People in charge forget that families are a key part of the solution."

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In the Courts:

Superior Court Affirms: 'Transfer Statute' Applies To Private Group Homes Federal Judge Tauro: Fernald Clients Must Be Allowed to Stay Home

In two unrelated but parallel cases, courts ruled that people with mental retardation could not be evicted from their long-term homes. First Federal Judge Joseph Tauro ruled August 14 that it was against the law for Governor Romney and the Department of Mental Retardation to coerce transfers out of the Fernald Center by unilaterally announcing that it would be closed. Fernald residents and their families and guardians must be offered the option of remaining at Fernald in individual ISP meetings. Governor Patrick has filed his intent to appeal that decision, but DMR must abide by the decision through the appeal process.

Superior Court Judge Geraldine S. Hines issued a preliminary injunction October 15 prohibiting the Massachusetts Department of Mental Retardation and Nexus, Inc. of Woburn from transferring Kristine Medeiros, 37, from her group home in Woburn without affording her the protections of M.G.L 123B, Section 3, the "transfer statute" which regulates the movement of mentally retarded people from their homes. (See "Know Your Rights, Page 2) Judge Hines specifically rejected the argument by DMR and Nexus attorneys that privately operated group homes under contract with DMR were not "facilities" regulated by Chapter 123B.

"This decision about one woman is an important precedent for the vast majority of the 32,000 people in Massachusetts with mental retardation/developmental disability," said COFAR President David J. Hart. "Judge Hines has made it clear that privatizing the system of care for people with MR/DD does not undo the rule of law protecting mentally retarded people served by the Commonwealth from being evicted from their homes. Private non-profits can't pretend that they are above the law."

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Tetrault Case

Claudia Tetrault, 53, has mental retardation and is also legally blind, non-verbal, and has had medical complications and behavioral issues. At age eight, she was placed at the Paul A. Dever Developmental Center and remained there until it closed,

then suffered serious neglect at a provider-operated group home, which was shut down. She had nine good years at a state-operated group home in East Bridgewater, where she made



Claudia Tetrault (right) with staff friend (Photo by Janet Topalis) attached to her day program. As her sister explains, “The staff there and at her day program became like family. It takes a long time to educate someone new into who Claudia is.”

Last April, however, DMR decided to close the East Bridgewater home and another in Quincy ostensibly to save money. (These homes were then reportedly to be contracted to private vendors.) Claudia Tetrault was to be transferred to another state-operated group home in Lakeville. Without the proper 45-day notice, without an ISP meeting, without any of

Know Your Rights: Chapter 123B, Section 3

COFAR and other family groups lobbied hard for this law. It guarantees that transfers of people with mental retardation require 45 days written notice to guardians, which has to include a statement of how the transfer “will result in improved services and quality of life for the retarded ward,” and the right of guardian to “examine” the new facility. Individuals and guardians may appeal, and no transfer can be made while the appeal is in progress. And, with Judge Hines’ recent memorandum in Medeiros vs. DMR et al, it has been upheld that the “Transfer Statute” fully applies to private contractors with DMR. . You can read it at: <http://www.mass.gov/legis/laws/mgl/123b-3.htm>

the legal requirements for transfer, DMR informed Claudia’s sister and Co-Guardian Janet Topalis – with a telephone call! As they insisted on Claudia’s rights, the tone became intimidating, with a warning that the transfer would take place.

The Lakeville home had three other residents, all using wheelchairs, and a swimming pool in the yard. With Claudia’s blindness and history, it was not a suitable placement. It was also an illegal transfer under Mass. General Laws Chapter 123B (see “Know Your Rights,” above), and a

violation of Claudia’s legal rights as a Ricci class member to “equal or better” treatment in any transfer. Meanwhile Claudia had an infection which required lengthy hospitalization. After advocacy from Claudia’s sister with advice from COFAR and the Dever Association, Claudia went from the hospital to respite care at the May Center of the Wrentham Developmental Center, June 14. With additional intervention from Senate President Therese Murray, Claudia has now been admitted as a permanent resident to Wrentham.

Medeiros Case

As reported here (See, “Advocacy Works” July, 2007), Kristine Medeiros, 37, lives in a group home run by Nexus, Inc., in Woburn. She has mental retardation and autistic tendencies, and developed retinal detachment in one eye since moving to the home five years ago. She is now blind in that eye. Krissy is verbal and friendly, although she can self-injure when frustrated or confused. She can write notes to her parents and house staff describing what happens to her. After a year of arguments about face guards and medication errors, including the family’s request for a new placement, Nexus notified DMR that it was canceling the contract regarding Krissy’s services effective August 28, 2007 and would evict her from her home of 5½ years. Meanwhile, a change of management at the group home has improved Krissy’s situation, so she and her parents would prefer for her to stay there. As in the case of Claudia Tetrault, Nexus and DMR gave no notice, no hearing, and the proposed new home, with lower-functioning (non-verbal) residents, does not meet Krissy’s needs.



After her parents won an injunction against the move, Nexus, backed by DMR attorneys, took the position that Chapter 123B, Section 3 does not apply to private contractors or any group homes! As this issue went to press, Judge Geraldine S. Hines has upheld the preliminary injunction, ruling that the “Transfer Statute” does apply to contractors and to group homes. (See “In the Courts” Page 1) Krissy’s parents have also filed charges with the Disabled Persons Protection Commission.

Carella Case

As reported here last issue, Ann Marie Carella, a resident at the Hogan Regional Developmental Center, has mental retardation and mental illness (Schizoaffective disorder), and numerous medical problems, including a susceptibility to several kinds of epileptic seizures. Her sister and guardian, Carol Carella, describes Ann Marie as “Full of personality. They say she is mildly to moderately retarded, but she has so much intellect that doesn’t show on the tests. She has a better

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memory than I do! She can't really write nor do arithmetic, but she scribbles and tries to do crafts and takes tremendous pride in her accomplishments. She loves to dance and sing, can be understood and is usually popular, but frequent mood swings severely impact her disposition."

Carol Carella, a nurse, traces her difficulties as a guardian with the Hogan administration back to early 2006, when Ann Marie had to stop taking Lithium because of kidney problems. This set off a chain of increased psychiatric problems, medication changes, behavior issues, seizures, medical problems, and disputes with administrative staff. (Our report was inaccurate in implying that the Hogan administration delayed a change in anti-psychotic medication for Ann Marie; despite some argument, the medication change was made immediately.)

Since our initial report, Ann Marie has had an alarming tendency to fall, and Carol has had to track these falls and try to intervene about their causes. Getting the staff to monitor levels of anti-seizure

medications properly, and reduce the falls from 40 April through mid-August (nine falls in the first half of August) to only one fall since. Getting staff to protect Ann Marie from excessive heat in August has also been a battle. And so was avoiding further injury to an already compromised immune-system damaged by the side effect of yet another medication. Carol has filed charges



with the DPPC. In meetings, Hogan administrators were not aware of all incidents of falls, seizures, and behavior problems, or deliberately under-counted them.

Carol persists because her advocacy makes a difference: "Since the Dilantin was reduced Ann Marie has demonstrated no seizure activity, and fell only once because she tripped over something. (Very recently she had three falls during a long weekend at home, probably because of another medication issue and the persistent problems in communication with staff.) In my opinion she is happier, more alert, animated, and interested in her environment. She enjoys and participates in her new Day Program [a retirement program with crafts instead of the greenhouse program] and is more spontaneous in expressing her wonderful sense of humor. I know Ann Marie is fragile, and I can accept it if she falls and is hurt in some situation that couldn't be predicted. But if she is severely

injured or dies as a result of their refusal to listen to me or to properly monitor her, or if they allow her to be in a dangerous situation that could have been avoided, I will always hold them responsible."

Alexander Case: What Advocacy Can Mean



The previous issue reported on the case of Carol Alexander, 54, who suffered a year and one half of unexplained injuries before DMR was persuaded to move her to respite care and another group home. Carol's sister Tracey Alexander now reports: "It has been almost 5 months since I pulled Carol out of the ARC group home in [North Shore town]. Carol remains injury free -- not one black-and-blue, not one cut, not one abrasion on her body. So much for [the former group home's] continued claims of self injurious behavior!"

"Carol is still amazing all of us with her new use of language. She not only is talking in sentences but actually stringing thoughts together. She actually initiates conversations with others, something she never did before. Her psychiatrist is just in awe of her, in total awe. He was nearly convinced that Carol was suffering from pre-dementia, convinced by the group home manager and the nurse practitioner in his practice. Carol is now totally weaned from her morning dose of Klonipen and will start weaning her 4 p.m. dose. In the next year Carol will be psych-med free, for the first time in seven years! All I can say is that for some group homes, it is easier to medicate an adult with MR than to try and talk to them."

"Carol and I went to Vermont again, and went apple picking, and Carol got to meet the new puppy that my sister has. She was in heaven playing with Sam. So, life has turned 180 degrees for Carol since she left [former group home] five months ago. I fill up with tears when I think about how abused and neglected she was, and how different her life might have been had we moved her when she got so silent, and they started medicating her."

DMR Waiver Change Aids Family Caregivers

DMR recently won renewal of its basic Medicaid waiver funding most forms of community-based treatment, but with one significant change affecting families caring for a loved one at home. In the renewal of the \$350 million DMR basic waiver, the state is now allowed to pay qualified non-guardian relatives for "extraordinary" care in the home. Thus meals or laundry would not be extraordinary, but many things family members do to keep a loved one at home can now be paid for at the same rates a similarly qualified worker would be paid at a group home or day program.

Meeting Commissioner Elin Howe A Wide-Ranging Conversation

DMR Commissioner Elin M. Howe and Assistant Commissioner Diane Enochs met with COFAR's executive board and more than 70 members from across the state for more than two hours at the Glavin Regional Center in Shrewsbury, October 2. The format began with a brief history of COFAR and introductions from each member of the audience, stating their names and the situation of their loved ones receiving DMR services. All regions, programs, and levels of satisfaction were represented. The Commissioner listened carefully and sympathetically, and alluded to people's stories later in the evening.



Commissioner Howe then gave a history of her own background and addressed some of the issues in COFAR's two-page agenda. She took questions from the audience for the final half-hour, and lingered to talk to individuals. On several points she requested time to get facts or promised to get back to us.

Elin Howe is a Massachusetts native and graduated from Salem State College, then moved to New York to attend graduate school at SUNY Albany. She has worked in the mental retardation field for more than 35 years, in both the public and private sectors, and for four years she was the DMR Commissioner in New York. In response to COFAR concerns about safety, Howe mentioned a period as the facility director at the infamous Willowbrook State School in Staten Island, and said she considers "safety and protection as the Number One issue in the care of persons with mental retardation." Commissioner Howe is currently living in Reading. She has a niece with mental retardation who is just turning 22 and has just entered the DMR system. "Therefore I know some of the demands on families who have a loved one with mental retardation."

In response to COFAR concerns about DMR staffing levels and training, she responded that service coordinators now have a caseload of 53 people each, but that her FY09 budget request would increase staffing to a 1:42 ratio.

Gail Orzechowski of The Advocacy Network, in Western Massachusetts, raised the question of proper burials for DMR clients, for which the law permits deductions from SSI benefits to a special savings account. In her experience, DMR service coordinators were not trained to set up these accounts, and at least one urn of ashes was still sitting in an office after a year. George Mavridis of the Fernald League added that this problem also affects Fernald residents, and a Waltham funeral direction provides some burials pro bono. Commissioner Howe was surprised to learn this and said she will assure that service coordinators are aware of the proper procedures.

On access to clinical services such as occupational and physical therapy (available at large facilities but not so readily available in many community settings), Commissioner Howe responded, "There will never be enough clinical therapists, and DMR must try and use those working at the developmental centers as a resource, as well as determining additional funding for clinical services."

On the ability of providers to terminate contracts with 60 days notice. (See, "Advocacy Keeps on Working," page 3), Commissioner Howe conceded that DMR is a "provider-driven" agency, since private providers serve 31,000 of 33,000 clients. Things will improve as DMR programs become "participant-driven" [clients and guardians contracting for services they want from an approved list]. About 300 families are now in that category.

Things will also improve when DMR establishes a "rate paying system" for negotiating with providers rather than negotiating long-term contracts.

In response to comments from COFAR Vice-President Thomas J. Frain on the high salaries paid to private provider executives, Commissioner Howe responded that DMR has no control over executive salaries, and providers may also have multiple sources of funding. She hopes that providers would voluntarily reduce CEO compensation and increase direct-care worker compensation. The provider contract system is part of a statewide "purchase of service system" not unique to DMR, and DMR is not responsible for writing the contracts.

In response to COFAR President David J. Hart's question about intimidation of families who question providers, including termination of contracts for their family members, Commissioner Howe said that she was saddened to hear of this and that it should be reported directly to her and others in senior management. She discussed QUEST as a tool to examine provider compliance and stated that provider reviews would be posted on DMR website.

COFAR asked about commitment to state-operated group homes. The Commissioner described herself as a longtime public employee and a firm supporter of this model, and will advocate increasing that budget line.

In response to COFAR's concern about eligibility barriers and inadequate service of young people turning 22, Commissioner Howe focused on the example of someone with Prader-Willi Syndrome (a genetic developmental disability) who couldn't meet the legal standard for mental retardation – IQ below 70 – but were clearly disabled and in need of services. By legal mandate, DMR, even with a name change, can only service people who fit the MR criteria.

In response to a number of questions about whether families are in fact offered facility placements as required by law, Commissioner Howe stated that there have in fact been 26 recent admissions to facilities. It was suggested that these were mostly Ricci class members exercising their right of return; Commissioner Howe did not have figures on that. She

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put the issue in the broader context of the difficulty of younger clients obtaining any kind of residential services. Residential options are really only given to a DMR client in a crisis situation – single, elderly parent/caregiver, unable to continue. Families must meet the MASSCAP requirements for residential services in addition to DMR eligibility. Commissioner Howe is looking into trying to increase residential services. Commissioner Howe stated that most students in residential schools would qualify for DMR residential services on turning 21, but was contradicted by a couple in the audience whose daughter in residential school had been denied.

In response to questions about long-term care and the role of the six remaining developmental centers, Commissioner Howe stated that DMR has “No plan to close any facility and that includes Fernald. The Governor has stated that Fernald is “moving toward closure.” DMR will comply with Judge Tauro’s order pending appeal, and is working with all Fernald families who show an interest in relocating their loved one during the court appeal. DMR has four unoccupied state-operated group homes waiting for Fernald residents. Two homes are at Glavin in Shrewsbury, one in Bedford and one in Millis. If the Fernald people do not chose the openings soon, DMR may offer them to people on the waiting list or in nursing home, or to others who qualify. She indicated that a decision about keeping the four homes empty or filling the beds would be made toward the end of this year.

Daryl Every, president of the Dever Association asked a question about the developmental model in planning high-quality day programming. For example, books, toys, and blocks that exist in schools that are not routinely used in day programs. Commissioner Howe agreed that attitudinal and practical changes need to occur. Again, a self-directed model could improve this situation. Day services continue to be a challenge for DMR.

Ed Orzechowski of the Advocacy Network talked about families being frustrated and do not know how to call DMR and talk about a problem. Advocacy Network has just set-up a hotline and the calls are coming in fast. Commissioner Howe stated that people can always call Assistant Commissioner Larry Tunmino or her office. There is also a DMR hotline number, but no one present knew what it was. Another suggestion the commissioner promised to consider was to return the position of DMR Ombudsman.

Coming Up Next Issue:

The politics of numbers: How exaggerated and inflated cost claims are dividing families and advocates for MR/DD, and why these bitter arguments are hurting everyone with any disability. It’s still about truth and falsehood, but it’s also about compulsory overtime, waste, mismanagement, irony, even a bit of corruption.

DMR Autism Waiver

November 5-16 are the crucial application dates for the new DMR autism waiver services. Although the autism waiver is only for three years, and for 80 kids up to age nine, it will fund early interventions not available through special education or regular Medicaid -- family-selected one-on-one habilitation/education services, up to \$25,000 per child per year. Early interventions can be life-changing in autism-spectrum disorders. Even with eligibility limited to family income at 150% of federal poverty guidelines (the level for MassHealth Standard), DMR has estimated that more than one thousand children may be eligible. Information in eight languages on how to apply is on the DMR website: www.mass.gov/dmr under “Autism Waiver Services Info and Forms,” to the right. Diagnoses on the autism spectrum include: Autistic Disorder, PDD-NOS, Rhett’s Syndrome, Childhood Disintegrative Disorder and Asperger’s Syndrome.

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President Hart praised Judge Tauro’s decision as “Telling Massachusetts – and probably warning every other state government – that the law does not tolerate the kind of intimidation families faced when Governor Romney announced he was closing all the large facilities, and the Department of Mental Retardation warned families and guardians that they better transfer their loved ones out of Fernald in a hurry -- because those who waited wouldn’t get any choice at all.”

COFAR Executive Director Colleen M. Lutkevich noted, “This was a real win - not just for the Fernald residents, but for everyone who has a loved one in the care of DMR. Their decision to appeal was a disappointment, because we hoped that DMR and the [Patrick] Administration would be ready to listen to families and negotiate seriously about the future of DMR - both in the facilities and in the community.”

Thomas J. Frain, vice-president of COFAR and an active lawyer-advocate for people with MR/DD, adds, “If you look at the Judge’s memorandum, he is really concerned with the integrity of the Individual Service Plan (ISP) process, by which people served by DMR can define what they need and how it will be provided. These plans have to be based on the individual needs of the person, not on what the state decides to make available. For most of the people who still reside at Fernald, that facility is the best possible option for them. The Court Monitor visited there often, and his report warned that transfers ‘could have devastating effects.’ When DMR unilaterally announced that they were closing Fernald, and that option would no longer be available, that violated the ISP rights of every Fernald resident. Now those residents, and others who have been in state facilities since before the court-ordered reforms, will have the option to remain in their longtime homes and enjoy the fruits of those reforms.”

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COMPREHENSIVE CARE
FOR ALL PERSONS WITH MENTAL RETARDATION

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