



The COFAR VOICE

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DDS guardianship policies raise concerns

Becoming the guardian of an intellectually disabled person is a critically important step in advocating on their behalf for adequate care and services.

But some COFAR family members are running into new obstacles in seeking to become guardians, including rising costs of guardianship applications and policies by the state that may discourage applications entirely.

Ed Orzechowski, a member of the Advocacy Network and a COFAR Board member, said that in addition to appearing to have inconsistent policies in helping family members apply for guardianship, the Department of Developmental Services provides no information on its website about how people can become guardians. (COFAR does provide guardianship information on its website at www.cofar.org, click on "Advocacy Guides.")

A long-held family secret is finally revealed to a Connecticut man about his intellectually disabled sister. A COFAR Voice feature story on Page 4.

Orzechowski and others maintain that the cost of attorneys needed to seek approval of guardianship applications in probate courts has become a growing problem. And Daryl Every, a special needs attorney and a COFAR member, says the cost of guardianship applications is also partly driven by the need in some cases for applicants to personally assemble a report from a 3-person clinical team as part of the petition for guardianship. The report must include stipulations from a physician, psychologist, and social worker that the intellectually disabled person involved is in need of guardianship.

In cases in which a person needing guardianship is under 22 or is already in DDS care, however, the clinical report can be prepared without cost to a family member

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Wintry view of a portion of the farm operation at the Templeton Developmental Center. See story about the care at Templeton on Page 5.

Facility closures not helping community system

Day habilitation, family supports, service coordinators and other key elements of care in the Department of Developmental Services system are facing significant budget cutbacks in the coming fiscal year.

These cuts, which affect thousands of residents largely in DDS's community-based system of care, were supposed to be mitigated by savings in phasing down and closing four of the six remaining developmental centers in Massachusetts.

However, an examination of Governor Patrick's Fiscal Year 2012 budget shows it does not appear to carry through on the promise to plow savings in closing the Fernald, Monson, Glavin, and Templeton centers back into the community-based system. Instead of benefiting the community-based care, the developmental-center closures appear to be putting more fiscal pressure on the community system.

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"There was supposed to be major savings in closing the developmental centers," said COFAR Executive Director Colleen Lutkevich. "And those savings were supposed to be plowed back into the community-based system. But it's clear that's not happening."

Even the Association of Developmental Disabilities Providers, which has supported the closures of the state facilities, has acknowledged that the community-based system has not benefited from the closures thus far. Since early February, the ADDP has been calling on the administration and Legislature to prevent further cuts to day habilitation, family supports, and other community-based programs. The ADDP has described day habilitation services as a key component of the administration's "Community First" initiative, which is centered around the closures of the developmental centers.

In 2008, Health and Human Services Secretary JudyAnn Bigby claimed to *The Boston Globe* that the administration would be plowing \$45 million a year back into the community system as a result of the shutdowns of the developmental centers.

Instead, key community-based line items facing cuts or inadequate funding in the FY 2012 budget include the following:

- DDS respite and family support: The ADDP is calling for an increase of \$17.9 million in this line item in order to prevent the loss of in-home supports to 4,000 families.
- DDS community residential: The ADDP says this line item needs an additional \$7.75 million to prevent the under-funding of a settlement in a court case that released thousands of persons with intellectual disabilities from nursing homes.
- MassHealth day habilitation and adult foster care: The ADDP says this line item needs an additional \$11 million to prevent cuts to programs affecting more than 7,600 people with intellectual and developmental disabilities.

In addition, the ADDP notes that direct-care workers in the community-based system have gone without pay increases for the past three years because the administration and Legislature have failed to fund a salary reserve line item for that purpose. The ADDP is asking for \$28 million to fund that account.

Meanwhile, COFAR is recommending that Governor Patrick examine the salaries of executives of contractors in the DDS system of care as a way to cut costs. In contrast to the low salaries made by direct-care workers, highly paid executives of the firms employing those workers appear to constitute a layer of bureaucracy in the DDS system that is "soaking up state funds," according to Lutkevich.

COFAR continues public records appeal

COFAR is continuing an appeal process to obtain public documents shedding light on the Patrick administration's claim that closing three developmental centers in Massachusetts will save taxpayer funds.

In early December, COFAR first sought records from the Department of Developmental Services backing up the claim that the closures of the Monson, Glavin, and Templeton centers will save \$20 million a year.

It was only in mid-February, after COFAR had appealed to the Public Records Division, that DDS provided any documents in response. The six pages provided, however, do not appear to be fully responsive to COFAR's records request.

The DDS provided a two-page letter and four pages of short spreadsheets. COFAR reviewed those documents as well as the administration's analysis provided last summer to the Legislature of the costs of developmental center versus community-based care.

Among other things, the records indicate that the administration performed two separate cost analyses – one which primarily used DDS budget costs, and a second analysis which factored in a limited number of additional fringe benefit and other non-DDS costs.

The documents indicate that the first analysis used a per-resident cost of operating an unidentified community-based group home housing former residents of the Fernald Developmental Center in order to project a \$14.7 million annual savings in closing the Templeton, Monson, and Glavin developmental centers. COFAR questions the validity of basing a calculation of the cost of community-based care on the cost of care of just one group home.

In addition, the documents provided by DDS do not indicate whether the cost calculated for the group home included transportation, medical, day habilitation, and other costs that are normally involved in community-based care.

The second analysis appeared to be based on state budget line items for community residential, state-operated residential, day, and transportation programs. It wasn't clear, however, whether medical, day habilitation, service coordination, and other costs were included in that analysis as well.

As a result, COFAR asked on February 22 to continue its appeal to the Public Records Division for DDS records and sent a follow-up request to DDS on February 23 for additional documents and analyses backing up the costs cited in the second analysis.

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applying for guardianship.

Every and others maintain that the combination of the attorneys fees and a lack of help from DDS may be resulting in fewer guardianships being processed.

Colleen Lutkevich, COFAR executive director, said that while she hasn't seen evidence that DDS has explicitly discouraged family members from becoming guardians, she has seen efforts to limit guardianships to such things as medical issues. Family members are often discouraged from becoming representative payees of residents of group homes, for instance, Lutkevich said. A representative payee handles a resident's Social Security and other funds.

"Some people are told (by DDS vendors) they're not even allowed to become rep. payees, Lutkevich added. "I question the legality of this."

Lutkevich contends that family members should continue to fight to become and remain guardians and representative payees of their loved ones in the DDS system. Guardians have important legal rights in the care of their wards with intellectual disabilities. They are a party to the Individual Support Plan (ISP) process and must give their approval to all ISPs and ISP modifications. If a guardian objects to an ISP or an ISP modification, he or she has the right to appeal it.

Guardians who are having difficulties with DDS should contact COFAR, which can offer advice and help walk people through the system.

Corporate guardians

Lutkevich and others argue that that family members usually make much better guardians than corporate entities or appointed attorneys. A guardian who is also a family member tends to act more often than not in the ward's best interest. Corporations or attorneys may not always do that. A case in point is that of Anna Tross.

Tross was a 91-year-old resident of the Fernald Developmental Center, who was removed against her will from the facility in 2008 and sent to a community-based group home in Bedford, according to court records. Tross's transfer had been approved by her corporate guardian, the Arc of Greater Boston. Tross died about a year later in the Bedford residence.

Proposed legislation that would make it harder for DDS to recruit corporate guardians in cases in which parents are seeking guardianships of intellectually disabled persons is currently pending.

In two separate cases, which *The COFAR Voice* examined, parents of DDS clients with attorneys appointed as the guardians have complained of ill treatment by those attorneys and of severe restrictions even on visiting their children in DDS care. In one of those cases, the DDS client's current guardian is an attorney with reportedly over 100 DDS wards.

In response to written questions submitted to DDS in January, Jackie Berman, DDS deputy general counsel, stated that the Department presumes that family members are best suited for guardianships and seeks out family members prior to consulting with anyone else for that purpose unless the family member is found to be unable or incompetent to serve.

DDS currently contracts with close to 70 attorneys and six corporate entities to provide guardianship services, according to a list provided by Berman.

Berman said DDS does not have written policies concerning guardianship or applications for guardianship, but that the Department complies with state regulations and with the Uniform Probate Code.

However, the lack of such written policies may result in some seeming inconsistencies in DDS's actions and advice regarding guardianship. Orzechewski said, for instance, that while some members of the Advocacy Network have been told by DDS that they must hire their own attorneys in applying for guardianship, one member acquired guardianship of his sister through the Department at no personal expense.

In addition, Peter Wyman, who cares for two intellectually disabled young men in his home, said he has been discouraged by an apparently unwritten DDS policy that prevents him from receiving state assistance for their care and being their guardian at the same time.

Berman stated that this policy is intended to prevent a conflict of interest in which a paid provider might not act in their ward's best interest. But Wyman said the policy also prevents him from advocating effectively on behalf of the men in his care. "The bottom line is I want them home and am willing to do all the work involved in keeping them home, but I need someone in DDS to think outside the box," Wyman said. He said he has written to Commissioner Howe and even to Senator Kerry, but has not received any help.

We still need your help

We offer our sincere thanks to everyone who responded to our appeal in our January newsletter for contributions to keep our work going.

With your help, we will continue to research and write about the issues that are most important to you and your loved ones, and we will continue to advocate on your behalf on Beacon Hill and across the state. But we need your continued contributions if we are to maintain our political pressure, scrutiny, and advocacy through our bimonthly newsletter, our blogs and press releases and much more.

We greatly appreciate whatever you can give. Please think about donating on a monthly basis, whether it's \$10 or \$50 to help us reach fiscal sustainability.

Thanks!

Revealing a painful secret Man learns late of sister's existence

One morning in 1985, when Herb Rosenfield of Cheshire, CT, was driving his mother back to Bradley Airport for her flight back to her retirement home in Florida, he happened to say something to her that triggered a major change in his life.

Rosenfield, a licensed clinical social worker who was then 40 years old, was describing his private practice as a therapist and was saying that he helped people "take skeletons and secrets out of the closet and heal from life experience."

His mother listened and said nothing unusual in reply, he recalled in an interview with *The COFAR Voice*. But a few days later, she called his wife, Linda, and told her she had something she wanted to share with her, but that she shouldn't tell her son. Linda said she couldn't promise she would comply with that request, adding, "Herb and I don't keep secrets from each other." Rosenfield's mother nevertheless revealed an astonishing piece of information to her.

Herb Rosenfield was not, as he had always been told, his parents' first-born child. He had an older sister named Sandy, who was profoundly intellectually disabled and was living at the Wrentham Developmental Center in Massachusetts. Other members of Rosenfield's extended family, as well as neighbors in his hometown of New Bedford had always known about his sister, but they had all been instructed not to say anything about her either to Herb or to his younger sister, Cindy. For 40 years, that secret had been scrupulously kept by all of those people.

For six months after getting this news from Herb's mother, Linda Rosenfield debated with herself and with her mother-in-law about how she might break the news to her husband. She was afraid Herb might be angry with his mother, who was by now a widow, and was also concerned he might decide his sister should be brought home to live with them. But, says Rosenfield, his wife's fears were unfounded.

When his wife did finally tell him about his sister, Rosenfield said that while he was shaken by the news and did experience some initial anger toward his mother and his relatives who had kept the secret, "I didn't castigate my mother or send poison-pen letters to relatives or want to take Sandy home with us for the rest of her life." What Rosenfield did do was to get in touch with the Wrentham Center, where he found out that his sister was indeed still living, and he became her guardian.

Rosenfield said his sister is nonverbal and has the intellectual capacity at best of a nine-month old. He visits her as often as he can and participates in her annual Individual Service Plan meetings. "There isn't

and will never be any recognition of me," by his sister, he said. Sandy Rosenfield is 66, a year and a half older than Herb.

A tragedy strikes

Rosenfield's mother was born in Russia and his father in Poland, and both were brought to America as children by their parents, who settled in the Fall River and New Bedford areas respectively. Rosenfield's parents met after they were grown, and got married in 1941. But tragedy struck three years later, when, during Sandy's birth, her umbilical cord got wrapped around her neck, cutting off her supply of oxygen and causing her later intellectual disability. For the first year of Sandy's life, Rosenfield said, Sandy had severe medical problems as well, which prevented her from sleeping through the night and keeping food down.

A doctor told Herb Rosenfield's mother that Sandy was likely to die within six months. The doctor also told his mother, who was now pregnant with Herb himself, that continuing to try to care for Sandy could damage her pregnancy and that she should place Sandy in an institution. Rosenfield's mother and father agreed to this, and first placed Sandy in then Tewkesbury State Hospital and later in the Wrentham Center.

Rosenfield said his parents instructed their relatives and friends that they themselves would tell their son and younger daughter about their older sister "when we were old enough to understand." But somehow that appropriate time never came. He said he believes his parents' motivation in keeping the secret from him and his younger sister was to spare them pain and unhappiness, and prevent further pain to themselves in discussing it. But that secretiveness led to a number of ironies in all of their lives.

When Rosenfield was 12, his mother happened to tell him, while discussing "the birds and bees," that his own birth had been the result of "an error in the rhythm method."

"I couldn't understand why, after four years of marriage, they weren't ready to have me," he said. His mother gave him some vague reasons about financial difficulties, which didn't satisfy him. Had she told him the real reason was that they were dealing with the recent birth of his older sister and all the attendant problems, "that would have made it understandable."

The secret may have contributed to the tragedy of his younger sister's suicide when she was just 22 years old. Rosenfield said he has no reason to believe Cindy ever found out about her older sister. She had been married for two years and was living in California when she took her own life. She left a cryptic suicide note, and Rosenfield said he never understood why she killed herself. But he thinks one possibility is that his parents had put subtle pressure on her "to be their special child

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in order to make up for their damaged first daughter." They did give her a similar sounding name to her older sister's, he said.

Cindy always seemed to handle that pressure well, Rosenfield said, and excelled in school and in college. But the unspoken pressure may have become unbearable to her.

Another irony resulted from the secret after Rosenfield had married Linda 1971 and they were living in Norwood, Massachusetts. Linda, at the time, was teaching elementary school in Wrentham, and happened to drive past the Developmental Center every day for years. "Neither of us had any clue my sister was living behind the walls there," Rosenfield said. A number of his relatives knew his wife was teaching in Wrentham, yet no one broke the family secret even then.

Rosenfield believes that had he known about his sister in the 1970s, he would have had an additional 15 years to help improve the generally poor conditions under which she was then living. By the time he first met his sister in 1985, conditions at Wrentham and other developmental centers in Massachusetts had begun to improve as a result of a federal consent decree case. But Rosenfield said that while there were a number of highly dedicated staff by that time, there were still problems with his sister's care.

Rosenfield said when he first met his sister, she was spending most of her day lying in a seat in the day room in a contracted position and had frequent urinary infections and constipation. As time went on, things began to improve. Rosenfield used her trust funds to pay for railings in the hallway outside his sister's bedroom. Today, Sandy is able to use a walker and is healthier in her 60's than she had been in her 40's, he said.

"I've been very impressed and very appreciative of my 25 years of contact with the Wrentham staff," Rosenfield added.

Rosenfield said the key lesson he would impart to others from his experience is that family secrets, even well-intentioned ones, "disproportionately have a way of doing damage." Not only did the secret in his own family have a negative effect on his own life and likely that of his younger sister, but it undoubtedly caused tensions between his parents and other extended family members who felt forced to keep the secret from him.

"There are professionals out there to guide people through the process of divulging something painful to family members," Rosenfield said. He said he personally tried to be as open as he could to family and friends when he found out about his sister.

"I have a Chinese proverb on the wall of my office," he added. "It says 'the best way to a good life is to take the good advice you give to others.'"

Templeton answers prayers

Jimmy Holdsworth kept getting thrown out of community-based group homes and sheltered workshops because his behavior was too volatile and his size and strength were too much for the staff to handle.

For Tony Welcome, community-based programs were ineffective in getting him to stop stealing cars.

Bobby Shepherd's habit of wandering and trying to make friends with strangers frequently got him into trouble, and community-based programs didn't provide the structure and supervision he needed.

In each of those cases, the Templeton Developmental Center turned out to be the solution to years of pain and struggle, not only for the men, but for their families. But it's a solution that will no longer be available to those families or the families of the 103 other remaining residents of Templeton as of the end of Fiscal Year 2013.

The Templeton Center is one of four state-run Intermediate Care Facilities in Massachusetts that the Patrick administration has targeted for closure. The others slated to be closed are the Fernald, Glavin, and Monson developmental centers.

Families and guardians of the residents of the facilities have protested the planned closures and, in the case of Fernald, have filed administrative appeals of the transfers of the residents.

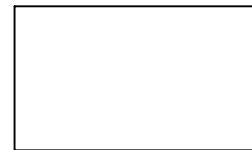
But as many guardians see it, it's not the closures of the buildings that make up the developmental centers that are at issue; the problem lies in the planned elimination of the federally prescribed level of care provided in them.

At Templeton, for instance, the administration plans to continue to operate three existing residences for persons with intellectual disabilities as community-based programs and to build two additional duplex homes on the grounds. Those residences, however, will no longer be subject to federal ICF regulations governing staffing and care.

As far as Bobby Shepherd's brother and guardian, Tony, is concerned, it will no longer be beneficial for Bobby to continue living in his residence at the Templeton Center following a change from ICF-level care there to community-based care. Tony Shepherd is concerned that under the community-based care model, the intensive clinical and medical supports that have sustained Bobby for more than 50 years will be greatly reduced.

Adds Judith Holdsworth, Jimmy Holdsworth's sister and guardian, "Everyone at Templeton can tell when something is bothering him. That's part of the miracle that occurred with my brother." (Please see the COFAR blog for more on the Templeton story.)

COFAR
3 Hodges St.
Mansfield, MA 02048



COFAR is a family supported, education and advocacy organization funded by member families.

Phone: 508-339-3379

Fax: 508-339-5034

Thomas J. Frain, President, Thomas.frain@cofar.org

Colleen Lutkevich, Executive Director, colleen.lutkevich@cofar.org

David Kassel, Newsletter Editor, dkassel@earthlink.net

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