

Report to the Developmental Disabilities Council
From
The Advocacy Center
October 2011

(1) We learned last March that a Chisholm class member had had his name taken off the waiting list, without his mother's knowledge, because she supposedly had not returned a letter OCDD had sent to confirm information on the registry. This led to his not getting the benefit of Chisholm procedures when his services were being prior authorized. It turned out that the validation letter had been sent to the wrong address. OCDD had his correct address, as did Medicaid. We got him immediately restored.

We followed up to find out how many people had been taken off the registry that way. What we found out was that **1,991 people** had been taken off since April 1, 2010!

DHH tells us that since May of this year all of these people have been restored to the waiting list with their original waiting list dates.

(2) In following up on this situation, we also learned that OCDD had been removing people from the list who had been offered and accepted a waiver slot, but did not return their 90L within a certain amount of time. These people were not getting waiver services and were no longer on the waiting list. We found out that 14 people were removed from the list before July 1, 2010, and 34 people were removed from the list after July 1, 2010.

OCDD states that all 48 of these people now have been linked to service coordinators, who should help them get a 90L and access NOW services.

(3) We have spent countless hours trying to insure that service coordination actually helps our Chisholm class members access the services they need. We developed training materials for service coordinators, helped develop forms that they have to fill out to insure that class members' needs for services are being explored and recorded, and forms they have to fill out to make sure that case managers are helping them actually get the services they need.

AC staff member, Jeanne Abadie (and former member of the DD Council) "monitors the monitors" by reviewing the records of Health Standards' annual monitoring visits.

It is a monotonous, detail-oriented job. In general, she has seen improvement in service coordination agencies over the years. But this year, she had serious concerns about one-the Columbus Organization in Kenner, not contacting clients monthly, not having face-to-face meetings as required, not returning clients' calls, and not following up to make sure clients were receiving services.

In July, Jeanne asked DHH for a plan to show that Columbus was either brought into compliance or replaced as a service coordination agency. They responded that HSS had shortened the license period (gave them a "provisional license" for 6 months), was "considering" sanctions, and (after Jeanne's letter) had called the Columbus administrators and gave them a good talking-to.

Jeanne wrote again, asking for specifics. This time she got a response that in August (again, after Jeanne's letter), HSS had decided to fine Columbus \$8000 for the deficiencies

(4) I am reporting the following success, which was negotiated between DHH and AC's contract attorney, David Williams. It is pretty significant and exciting and I think we should give our state a pat on the back for being progressive in this area:

Louisiana is First State in the Country to Expand Eligibility for Home and Community Based Services

Many seniors and people with disabilities who can no longer take care of all their needs are caught in the middle. They receive too much money to qualify for Medicaid-covered "home and community waiver" services, but not enough to pay for these services out of pocket. Until recently, they were forced to abandon their homes and communities, lose their connections to their natural support systems and move to a nursing home to qualify for Medicaid-funded care.

Until now, in Louisiana and all other states, there has been an income cliff—\$1 above the limit, and no help at all was available unless you moved into a nursing facility. The Louisiana Department of Health and Hospitals has changed that. Now those with incomes over the limit can get services too. Louisiana is the first state in the country to receive federal approval for this type of expansion.

"This eliminates a fundamental unfairness, where having a few more dollars in income meant losing access to services that can cost thousands of dollars," said David Williams, the attorney who spearheaded adoption of the change.

Before this policy change, only people with monthly incomes under \$2022 (for an individual) could qualify for home and community based services even though people living in nursing homes could qualify for Medicaid with incomes over twice that high.

Most of the new higher-income individuals will have to contribute to the cost of their care, as nursing home residents do. But, because people who live in the community have to also pay to maintain their homes, the amount they contribute will be less than it is for facility residents.

The programs affected, the Elderly and Disabled Adult (EDA) and Adult Day Health Care (ADHC) waiver programs, still have an asset limit. People have to spend down most resources (other than their home, one car, and some other exemptions) to under \$2000 to qualify.

“This is an important step. Unfortunately, our state has over a two-year waiting list for the services. So people need to get on the waiting list long before they actually need services,” said Mr. Williams.

For information about any of these programs or to apply for services, call the Louisiana Options in Long Term Care Hotline at 1.877.456.1146 (TDD: 1.877.544.9544). You can call Monday through Friday between the hours of 8 a.m. and 5 p.m. The call is free.

Anyone denied eligibility for the EDA or ADHC programs due to too much income since December 1, 2010, should contact the Advocacy Center’s Intake Unit at 1-800-960-7705 (Voice), 1-866-935-7348 (TTY) or advocacycenter@advocacyla.org.

(5) And, finally, here is the saga of three individual cases handled by AC staff:

Client Gets to Keep Waiver Services

The Advocacy Center was appointed on June 30 to represent “Daisy” in an adult protective services petition hearing scheduled for July 7. The client, via temporary court order, was removed from her supported independent living apartment and placed in a group home. Allegations were that Daisy refused to take her medication, was abusive toward her staff, was not addressing hygiene issues, and allowed strange men into her apartment on occasion.

The Advocacy Center met with Daisy at her group home on July 6. She was adamant that she wanted to return to her apartment, her friends, and her town.

The July 7 hearing took an entire morning. OCDD, a social worker, Daisy’s provider agency, and a psychologist all testified that Daisy should remain in DHH custody and in the group home. AC’s attorney, Mark Perron hammered at the fact that after 30 days Daisy would lose her waiver slot and be placed on at least a seven-year waiting list. Perron was also troubled that there was no recent psychological evaluation attached to the petition and that the allegations did not rise to the level of requiring protective services.

The regional director for OCDD testified that Daisy needn’t necessarily lose benefits, that there was a separate fund-Community and Family

Supports-that could be used to provide Daisy services if she lost her waiver.

At the close of the hearing, Mr. Perron argued for the judge to hold off on his judgment until the results of a psychological examination were in hand. The hearing was continued for two weeks.

In the meantime Mr. Perron obtained information about the exact dollar amount the OCDD Region in which Daisy lived received for Community and Family Supports for 2011. After reviewing the figure, he came to the conclusion that if they used that money to provide services for Daisy, she would be about the only client they could help.

When Mr. Perron returned to court, he told the OCDD Regional Director that he would absolutely hold him to the use of the C&FS funds to assist our client if she continued to live in the group home and lost her waiver slot.

OCDD stated they could hold her waiver slot for 60 days; and the judge agreed to hold a review hearing within 60 days rather than the usual 6 months. Meanwhile Daisy would remain in the group home. She broke down and sobbed hysterically, as she did after the first hearing.

On September 7 the Advocacy Center met again with Daisy in her group home. Daisy cried, and pleaded for help to “go home to my apartment, my friends.”

On September 8 the Advocacy Center received a call from the Regional OCDD Director. “You were right. Of paramount importance is that Daisy not lose her waiver services and waiver slot. We don’t wish to use the limited Community and Family Support fund for this purpose. We will allow Daisy to return to her apartment.”

Normally, when DHH files for protective services or judicial commitment, the allegations are strong and the best the Advocacy Center can do is negotiate services or programs for our clients. Rarely do we flat out prevail. It is usually, as here, one lone client (often scared and inarticulate) against an array of folks from DHH, OCDD, provider agencies, and psychologists. In this case, the Advocacy Center successfully educated the judge on waiver programs and the importance of not losing these services lightly. Review dates were moved up. And OCDD eventually saw it “our way.”

Client Doesn’t Want Waiver Services

“Paul” has a mild developmental disability and has had issues of homelessness, bad check writing and failure to pay child support. He has also abused drugs and alcohol.

In June, Mr. Perron met with Paul and representatives from OCDD, APS, DHH, social workers, and Paul’s provider. The result was that Paul’s service hours were cut from 24/7 to three hours in the a.m. and eight hours in the p.m. Weekend service hours were from 6:00 a.m. to 10:00 p.m. This was a step in the right direction for Paul, who also wanted to control his finances.

In late August, Paul again wanted to withdraw from the Waiver program. Another meeting was called on September 6 and the same people attended. Paul’s Advocacy Center attorney was concerned that if Paul withdrew from services and APS filed for protective services, that a judge might reinstate Paul to 24/7 care. (Client has a long and recent history of behavioral issues that might have persuaded a judge that he needed more, not less, oversight.)

The result of this second meeting was that Paul’s weekend hours were cut in half, and he will be allowed to handle his finances for a three-month trial period. If it works out, Paul will continue to handle his finances after the trial period ends.

Paul is a likeable, though difficult, client. Although he has received extensive assistance from the Advocacy Center, he is a good “self advocate” and further proof that “the squeaky wheel gets the grease.” Eventually his service hours will be whittled down to just a few a day, making him more content.

Client Wants Waiver Services But Is Impeded By One Employee

The Advocacy Center represented “Carl” a few years ago when he was under a judicial commitment and placed at the Ruston Developmental Center. Carl was transferred to Pinecrest Developmental Center when Ruston closed. Some months ago, his “team” recommended him for independent living. However, one member of the team was dragging her heels on the transition, insisting that Carl was still under judicial commitment. This lone individual did not think that Carl was appropriate for community living. The Advocacy Center Client Advocate for Pinecrest assembled all the background information and then requested assistance from AC’s legal department.

First, the Advocacy Center obtained confirmation from the Ruston DHH attorney that he deliberately let the commitment lapse and no longer had custody of Carl. The Advocacy Center next obtained confirmation that the

DHH attorney for the Pinecrest area had no intention of filing for commitment.

With this information, the Advocacy Center sent a strongly worded letter to the person holding up the transition. In no uncertain terms, we stated we wanted the transition completed. Within days the Advocacy Center received a telephone call from the OCDD Regional Director, stating that as a result of our letter, Carl was to be "fast tracked" for transition.

On the authority of the Regional Director, Carl will move into his own apartment just as soon as one can be located.