

Advocacy Center
Quarterly Report to the DD Council
(December 19, 2012)

Update/progress on agency initiatives

1. Update on Bayou Health and Waiver recipients:

DHH has put out a request for ideas from managed care providers about how to provide long term care services under managed care. The request seeks input on providing waiver services and institutional services through managed care, as well as on providing acute care services to waiver populations, which are currently excluded from Bayou Health. Responses are due by January 28, 2012.

The Advocacy Center will be following this process closely and will be advocating for a system that gives clients a meaningful choice, high-quality healthcare services, and increased access to home and community based services. We will oppose any plan that provides managed care companies with incentives to restrict or deny home- and community-based services (such as by including HCBS, but not institutional services, in managed care).

It is our understanding that waiver recipients will not be required to choose a Bayou Health plan, pending the results of this process.

The Advocacy Center hopes to collaborate with the DD Council on this initiative.

2. Issues regarding the NOW waiting list and utilization of the ROW:

The Advocacy Center remains concerned about seeming inconsistencies in the NOW waiver waiting list and the number of unfilled slots in the ROW waiver. We are in the process of obtaining additional information from OCDD and Medicaid.

We have several clients who have been told that they are "next on the list" for the NOW waiver, because they have registry dates that pre-date the current offer date; however, they are not being offered slots and have been given no date by when they can expect an offer.

We are currently gathering more information from state officials and would appreciate hearing from individuals who have recently received a NOW or ROW waiver or are close to the "top of the list".

3. Bayou Health issues

The Advocacy Center continues to receive complaints from individuals whose services have been denied or reduced without notice, by managed care companies. Most of these cases involve very young children who are receiving home nursing services and related supplies. We recently met with a team from one of the managed care companies to discuss their approach to prior authorization. We

emphasized the critical needs of these children for prompt prior authorization, no breaks in service while prior authorization is being considered, clear instructions to providers as to what information and documentation is needed, and clear and detailed notice of the reasons for any denials. We hope this will lead to improvements in this provider's systems.

If you or someone you know is having trouble accessing services or equipment through Bayou Health, please let us know.

4. Coordinated System of Care and Magellan

In 2013, the Advocacy Center will have a public health student and a social work student assisting us in tracking individual and family experiences with Magellan and the Coordinated System of Care (CSoC), the specialized program for children with significant behavioral health issues who are at risk of institutional placement.

One concern regarding CSoC is the upcoming move to a one statewide Family Support Agency, rather than local agencies. We will continue to monitor this transition.

In addition, we are concerned that individuals with mental illness receiving services from Magellan are not receiving adequate notices when services are denied or are not provided in the scope or duration requested.

If you or someone you know is having trouble accessing services or equipment through the Coordinated System of Care or Magellan, please let us know.

5. Employment First

The Advocacy Center remains concerned about the slow pace of movement in implementing Louisiana's Employment First plan. We hope to work more closely with OCDD and the DD Council to ensure the Employment First plan is designed to ensure real change and that it is fully implemented soon.

6. AC Helps to Ensure the Right to Vote for People with Disabilities and Seniors on Election Day 2012

Ensuring the right to vote for people with disabilities and seniors is an integral part of the Advocacy Center's work. On Election Day 2012, AC operated a hotline to answer voting questions and record complaints about the voting process. Hotline staff encountered such issues as: problems with the physical accessibility of polling places; problems with the audio ballot function for people with hearing impairments; and problems for people who needed assistance with voting.

Some of our Election Day 2012 stories:

- The accessible entrance of one polling place was located far from its permanent accessible parking spaces. People with disabilities were having trouble with the long walk. AC was alerted to this situation via our hotline, and our staff went to the polling place and, with polling staff, were able to designate temporary accessible parking near the building's accessible entrance, thereby making it much easier for people with disabilities to enter the building to cast their ballots.
- One of AC's advocates discovered that the long-term psychiatric hospital she monitors did not have a plan in place to allow its residents to vote in the community. Their only option was to vote via absentee ballot, an unnecessary restriction. Our advocate worked with hospital staff to develop a policy allowing residents who were able to vote in person in the community to do so.
- One client in the abovementioned hospital hadn't voted in 4 years because no one had offered to update her voter registration. AC's advocate took care of that for her, and she was able to vote for President!

If you experienced a problem voting on Election Day, or during early voting, please contact the Advocacy Center.

7. Recent Successes

Ms. M. is a 45 year-old woman with cerebral palsy who receives Medicaid waiver services through the Office for Citizens with Developmental Disabilities (OCDD). She called the Advocacy Center for help because, during an annual review, she was wrongly told that she had to agree to a reduction in her waiver hours. Feeling she had no choice, Ms. M signed a plan of care for reduced hours. Under OCDD policy, if Ms. M. tells OCDD within 30 days after signing that she wants her original hours back, OCDD is required to reinstate her original hours and provide her with appeal rights to challenge the reduction in hours. Ms. M. did notify OCDD within 30 days that she wanted her hours back, but OCDD failed to reinstate her hours and failed to inform Ms. M. of her appeal rights. An Advocacy Center attorney investigated the case and intervened on Ms. M.'s behalf. Because of Advocacy Center's assistance, Ms. M.'s hours have been reinstated. OCDD additionally agreed to investigate whether other waiver recipients were denied reinstatement and appeal rights and issued a statewide memorandum to remind all OCDD workers of these rights.

Ms. G, a young lady with significant physical disabilities contacted AC because Tulane University had failed to include wheelchair accessible seating when it remodeled an on-campus theater that hosts community events, plays, and other performances. AC investigated her claims and agreed to help her. The Advocacy Center attorney negotiated with the university to add accessible seating to the theater. Now, Ms.G is much happier because she can attend plays and other performances with her family.

Status of agency's activities/participation on DDC plan initiatives and impact

Objective 3.1 4,000 people on the waiting list will begin receiving home- and community-based services by educating stakeholders, policy makers and the public about the waiting list and needed systems reforms.

Activity 3.1.2 Collaborate with other advocacy groups to plan and support Disability Rights Rallies.

Activity 3.1.3 Advocate for systems change initiatives, revenue generating strategies, policies and practices needed to expand supports and services.

The Advocacy Center will help support the Disability Rights Rally and will support the DD Council's efforts to obtain additional funding for the NOW waiver in the 2013 legislative session.

Objective 3.2 Admissions to developmental centers will cease by increasing access to behavioral and medical intervention in the community and the discontinuation of people adjudicated into developmental centers.

Activity 3.2.1 Advocate in collaboration with the Advocacy Center for

- additional short-term emergency placement for behavioral and medical stabilization and
- improving the HCBS system by soliciting feedback from individual with behavioral and medical support needs using or having difficulty using the system.

Advocacy Center staff, in collaboration with the DD Council, are planning a meeting with Magellan regarding access to behavioral healthcare for individuals with intellectual disabilities in early January.

In addition, Advocacy Center staff will work with the Developmental Disabilities Council to further analyze barriers to medication administration by direct support workers and address these issues legislatively or through rule-making as appropriate.

Objective 7.4 Students will be protected from discipline practices that cause harm and/or violate their rights.

Activity 7.4.1 Educate legislators, policy makers and the general public about harmful practices (e.g., restraint and seclusion, corporal punishment, unnecessary use of law enforcement, etc.) and alternative positive evidence based options (e.g., positive behavior

practices, etc.) and advocate for policies and practices that promote the safe and effective practices in collaboration with the Advocacy Center.

Nothing new to report in this area.

Objective 9.1 Louisiana will develop and implement an Employment First plan.

- Activity 9.1.1** Advocate for
- sheltered workshops to transition people into individualized, competitive, paid employment and discontinue admissions into segregated day programs,
 - collaborative policy making and practices across state agencies that promote students being supported in and transitioning into competitive paid employment,
 - implementation of ongoing multiagency employment data collection, management and analysis.
 - LRS and OCDD will collaborate to mandate that all supported employment vendors/providers complete a university-based 40 hour training.

See the above report for information on the Advocacy Center's concerns regarding delays in implementing employment first.

Objective 9.3 The Louisiana Vocational Rehabilitation (VR) program's federal draw down will increase.

- Activity 9.3.1** Advocate for Louisiana to draw down the entire VR grant award and serve individuals with the most severe disabilities.

Nothing new to report in this area.

Objective 9.4 Family members and others will be knowledgeable about options for integrated, competitive employment in collaboration with the Advocacy Center and the LSU-HSC Human Development Center.

Ensuring access to competitive employment is a major systemic priority for the Advocacy Center in 2012-2013. AC will continue to collaborate with the DD Council and HDLC in this area.