

Advocacy Center
Quarterly Report to the DD Council
(March 26, 2013)

Update/progress on agency initiatives

1. Update on managed care for long term services and supports

In November 2012, the Department of Health and Hospitals released a Request for Information (RFI) regarding the potential use of a managed care organization for long-term supports and services.

The Advocacy Center has identified a number of issues that are key to this successful conversion:

- a. Inclusion of both institutional and home and community based services in the same managed care company. We believe that the inclusion of only home and community based services would create significant incentives for managed care companies to move higher need/higher cost individuals to institutions.
- b. Expectations that managed care companies take significant steps to reduce the waiting lists for home and community based services. The state should include clear benchmarks for this in the RFP and contract.
- c. Involvement of recipients of long-term services and supports and advocates in the design of the RFP and implementation.
- d. Inclusion of behavioral health and acute services within one managed care company. We believe this is the only way to ensure the needs of the entire person are considered and will improve coordination and use of preventative services.

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

The Advocacy Center continues to represent individuals currently on or inappropriately removed from the NOW waiting list. We remain concerned about inconsistencies in the management of the list.

Per the report at the last DD Council meeting, we are also concerned whether slots on the ROW waiver are currently funded and available to be filled.

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. Access to Applied Behavioral Analysis (ABA) for Children on Medicaid

On February 21, the Advocacy Center filed a motion in the Chisholm lawsuit to allow class members with autism or other pervasive developmental disorders (children ages 3-21 on the NOW waiting list) to receive ABA therapy. If successful, Medicaid will be required to enroll ABA providers and fund services for these children. A

hearing on this motion is scheduled for April 24th.

4. Coordinated System of Care and Magellan

Currently, the Advocacy Center has social work and public health interns examining the Coordinated System of Care (CSoC) in Louisiana to better understand how the system is working – or not working – for children and families. They are interested in talking to families about their experiences, and how CSoC can be improved. They are also interested in hearing from the people who are connected to these children and families, including providers.

As we understand it, children with developmental disabilities and mental illness who meet the other criteria can access CSoC services. If you or anyone you know has attempted to access CSoC services and you are willing to speak to our students, please let us know.

5. Radio Interviews with AC staff and Board members

In January 2013, Advocacy Center staff began a monthly interview series with one of 88.3 WHRB Reading Radio's most popular programs, the "Public Affairs Show". This station is broadcast in New Orleans.

Tune in on the last Sunday of each month to hear staff and board members of the Advocacy Center discuss the agency's work and current hot topics in the disability and senior communities. The "Public Affairs Show" airs at 7:30 a.m. with a rebroadcast at 8:00 p.m.

The show can also be heard live online at www.wrbh.org. Archives of past shows are available on Itunes: <https://itunes.apple.com/podcast/wrbh/id317212661?mt=2>.

Recently aired and upcoming topics:

January: Agency overview – Lois Simpson

February: Mental health issues/Lunch & Learn series – Cecile Tebo

March: Traumatic brain injury – Susan Bushnell and Madonna Franco

April: Legislative issues – Stephanie Patrick

May: Alternative decision-making (interdictions and POAs) – Koki Otero

June: Technology – John Felt

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6. Change in Policy: Client Contributions at LRS

The Advocacy Center recently approached LRS about its policies requiring clients to contribute to the cost of their vocational rehabilitation services.

Federal regulations prohibit LRS from using a financial needs test for clients who receive Social Security Income (SSI) or Social Security Disability Income (SSDI) or

requiring them to participate in the cost of vocational rehabilitation services. Yet, LRS asked some of these clients to contribute cash to the cost of establishing a small business.

AC CAP staff brought this to the attention of LRS's Director, who agreed to update the agency's policies to ensure that no client who receives Social Security Income (SSI) or Social Security Disability Income (SSDI) will be asked to contribute to his or her vocational rehabilitation services.

If you receive SSI or SSDI and were discouraged from starting a small business by LRS, or were otherwise asked to contribute to the cost as a condition of receiving vocational rehabilitation services, AC would like to hear from you. Contact David Gallegos at 1-800-960-7705 x141, or dgallegos@advocacyla.org.

7. Recent Successes

At one of the state run institutions, AC received a complaint from residents of a particular home. They alleged that they were forced to go to their bedroom and remain there for 3 days for engaging in "at risk" behaviors. While on bedroom restriction, they could not access personal belongings and were only allowed to leave their bedrooms for medication, bathroom breaks and mealtime. Other residents engaging in "at risk" behaviors are placed in an intensive treatment unit until their behaviors subside. When the AC advocate told the facility administrator about the complaint, he revoked this "solitary confinement" program.

Another complaint from residents of the same facility involved "active treatment". During the summer of 2012, there was a change in psychology staff at the facility and that is when the certain clients stopped receiving treatment. This was especially disturbing because many residents' treatment plans indicate that their discharge from the facility is contingent upon their completion of active treatment. Once this issue was brought to the administrator's attention, he agreed resume active treatment.

Through monitoring in the Chisholm case, AC learned that a Chisholm class member was given the 40 hours a week of home nursing service that her doctor recommended. This child had multiple serious disabilities and medical conditions, and her mother quit working to take care of her. The mother needed to work, but the child needed continuous medically-related monitoring and care. Medicaid denied all but 21 hours, stating that the child's doctor agreed that that was all the care she needed. AC represented the child at an administrative hearing in January. The judge reversed the denial, and the child is now receiving 40 hours per week of home nursing.

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 met with Magellan representatives and parents of individuals with intellectual disabilities and mental illness in January. It seems clear that there is room for better coordination for individuals seeking behavioral health services in the community to avoid institutionalization.

We welcome calls from individuals or families who cannot access the mental health services they need.

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.

Recent efforts by OCDD to convene the Employment First workgroup have been promising. We continue to work with them to develop a set of criteria and plan for data collection. We will continue these efforts. The Advocacy Center's Community Living Ombudsmen are in the process of gathering information on employment for residents of ICF/MR facilities.

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.

AC will continue to collaborate with the DD Council and HDLC in this area. Advocacy Center staff have recently attended support coordinator trainings on supported employment with OCDD and we look forward to continuing these efforts in the future.