

**Advocacy Center**  
**Quarterly Report to the DD Council**  
(September 26, 2012)

**Update/progress on agency initiatives**

**1. 2012-2013 Plan**

The Advocacy Center is planning increase resources to focus on systemic changes in 2012-2013. Our work will be focused in five areas: community integration, employment, voting, rights protection and education.

Below is a list of the major goals:

**Community Integration**

- People are able to remain in their homes, with the provision of Medicaid Home and Community Based Services.
- Children with behavioral health needs receive appropriate care in the community.
- People with disabilities have access to required health care through Bayou Health and Louisiana Behavioral Health Partnership (Magellan) Managed Care Programs.
- Barriers to exercising autonomy and living independently in the community are eliminated.

**Employment**

- Adults with disabilities are given opportunities to engage in competitive employment.
- People with disabilities have access to information, advice and representation in the area of rehabilitation services, and beneficiaries of Social Security are aware of their employment rights.

**Voting**

- Barriers to voting are eliminated and people with disabilities have an increased knowledge of voting rights.

**Rights Protection**

- The rights of children with disabilities who have been placed in residential facilities by OJJ, DCFS, or other state entities are

protected and enforced and they live in adequate and humane conditions, are able to access services in the community, and are able exercise autonomy to the maximum extent appropriate.

- The rights of adults with developmental disabilities living in residential facilities, including those in ICF-MR, are protected and enforced, and they are able to live in adequate and humane conditions, are able to access services in the community, and able to exercise autonomy to the maximum extent possible.
- Egregious conditions of neglect or abuse in prisons for people with disabilities are corrected.
- The rights of people with disabilities living in SIL in Jefferson Parish are protected.
- Conditions are improved, rights are protected and enforced and opportunities for community integration are increased for people with mental illness and traumatic brain injury living in nursing homes.

#### Education

- Children residing in child residential facilities obtain appropriate educational services.
- Incidences of illegal exclusions from schools for students with disabilities are reduced.
- Students with disabilities obtain appropriate transition services.

## **2. Bayou Health**

The Advocacy Center continues to monitor the inclusion of new populations into Bayou Health. Staff continues to encourage DHH to make Bayou Health optional for waiver recipients over age 19 who are not on Medicare or LaHIPP, to give waiver recipients the opportunity to opt into the program rather than forcing them to opt out, and to provide comprehensive, easily understandable information to help them to make a decision.

Due to their complicated health needs, waiver recipients often have multiple physicians and change is extremely difficult. The Advocacy Center has assisted a number of individuals who were auto-assigned to a Bayou Health provider and suddenly lost access to critical services. This is why the Advocacy Center is encouraging DHH to allow these individuals to opt in rather than forcing them to opt out.

In addition, the Advocacy Center has identified a number of potential systemic issues with Bayou Health including adequate and understandable notices that clearly explain the individual's right to appeal when services are denied or reduced.

### **3. Home Nursing Services Issues**

On June 26, 2012, federal judge Carl Barbier ruled that the Louisiana Department of Health and Hospitals is violating the settlement in *Chisholm v. Greenstein*, a class action brought in 1997 by the Advocacy Center in behalf of Medicaid-eligible children on the NOW waiver waiting list. The Advocacy Center brought DHH back to court last fall, alleging that DHH was violating the settlement by reducing or denying home nursing services to children without proper notice regarding the reasons and without sufficient information about the child's needs. Additionally, DHH's contractor often suggests personal care services instead of home nursing, without approving those services or informing parents and doctors about the limitations of the alternate services.

Judge Barbier ruled in favor of the Advocacy Center, and ordered the State to:

- In deciding whether to authorize nursing hours, consider the amount of services the child has received in the period immediately preceding the request, and whether the child's condition has improved or other circumstances make less care necessary;
- Approve hours prescribed by the child's physician, unless notices of denial explain evidence of improvement in the child's condition or other changed circumstances that make less care necessary;
- For requests submitted up to one year after June 26, 2012, approve the highest number of weekly hours the child has received from January 2010 to date, unless there is evidence the child's condition has improved or other circumstances make less care necessary;
- (If services are reduced or denied because personal care services can meet the need), include in its notices the number of hours of PCS that will be approved, based on information already submitted; specify whether an adult caretaker's presence is required; and state that the less costly service (PCS) will be approved if a prior authorization request is submitted and prescription is obtained.

The Department of Health and Hospitals cannot avoid these obligations by getting a statement from the child's treating physician that he or she now agrees to a reduced number of home nursing hours.

If you have any questions about this ruling, contact Nell Hahn at 1-800-960-7705, ext. 311.

#### **4. Coordinated System of Care**

Advocacy Center staff have been monitoring the implementation of the Coordinated System of Care, which serves children in need of behavioral health services who are at risk of institutionalization.

Major concerns include:

- The screening process
- Denials and appeal rights
- Access to individualized services for children with multiple disabilities

Please encourage parents to contact the Advocacy Center if they encounter problems in accessing CSoC or obtaining needed services.

#### **5. Preparations for the 2012 Presidential Election**

On November 6, 2012, voters across the United States will head to the polls to choose the next President of the United States.

Visit [www.geauxvote.com](http://www.geauxvote.com) to locate your polling place, confirm your registration and view your ballot.

Advocacy Center staff will be available to answer voting questions on Election Day (November 6<sup>th</sup> from 6:00 am to 8:00 or during early voting, October 23<sup>rd</sup>-30<sup>th</sup>). Call 1-800-960-7705 or email [advocacycenter@advocacyla.org](mailto:advocacycenter@advocacyla.org).

#### **6. Hurricane Isaac response**

Beginning on August 27, 2012, Advocacy Center staff stayed in close contact with the Governor's Office of Homeland Security and Emergency Preparedness, the American Red Cross, FEMA, LATAN, DHH, and other

organizations involved in response to and later recovery from Isaac. All of these agencies knew how to contact Advocacy Center staff and knew that the Advocacy Center was available to respond to issues relative to people with disabilities and meet those needs as best we all could. As issues were brought to our attention re: possible problems in the shelters, the issues were brought to the attention of national and state employees of the American Red Cross and those issues were resolved.

Advocacy Center staff visited one of the shelters to assure that the needs of people with disabilities were being met. The Advocacy Center believes that response and recovery relative to Hurricane Isaac went much smoothly because of our involvement in the Emergency Management Disability and Aging Coalition (EMDAC). Having the proper contacts with FEMA, GOHSEP and the American Red Cross would not have happened had we not remained a key player in EMDAC. The planning and preparation done by this Coalition was invaluable and work on this Coalition will continue with the intent of continuously improving Louisiana's ability to respond to people with disability and aging before, during and after a disaster.

## **7. Recent Success**

Mr. K, a long-time client of the Advocacy Center, has significant physical disabilities and uses a ventilator. Because of his medical needs, he was forced to live in a nursing home for many years. He hated it and vowed never to go back; he now lives in his own apartment on the NOW waiver. His health is very fragile - there is always a risk of infection, aspiration or pressure ulcer. In the face of these risks, AC has been battling for years to ensure Mr. K stays out of an institution.

Recently, Mr. K was told that he would need 24-hour skilled nursing in order to remain at home. This is extremely expensive and is almost unheard of for people on waivers. Mr. K, his provider and AC staff were really worried that, this time, AC wouldn't be able to keep Mr. K out of a nursing home. After two weeks of alternately begging and threatening, the AC attorney was able to negotiate successfully with OCDD. Mr. K now has his 24-hour skilled nursing with the company of his choice.

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

**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 health and medical stabilization
- For increased capacity of the HCBS system to address the needs of individuals with behavioral and medical support needs

*Advocacy Center staff continue to investigate access to adequate behavioral and medical health services for individuals living in institutions and in the community. AC staff have emphasized the important of coordinated and comprehensive care at recent meetings with OCDD and OBH. Staff was encouraged to learn that OCDD, OBH and Magellan are beginning to meet regularly to address individual problems and identify systemic solutions. Staff will continue to monitor the situation and welcome reports of problems.*

**Objective 3.3** The number of people in private ICFs/DD per capita in Louisiana will decrease to reach the national average through the transition of people to home and community based services.

**Activity 3.3.1** Advocate for:

- A Money Follows the Person (MFP) policy to allow residents of private ICFs/DD to obtain waiver services
- The MFP grant program to target residents of private ICFs/DD

*Advocacy Center staff discussed this issue with OCDD at a recent meeting. Reports that OCDD will not fill NOW waiver slots in 2012-2013 is very concerning and we welcome reports of individuals who are at risk or in an institution because of delays in accessing a waiver slot.*

**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.

*Because a lack of reports on this issue despite significant outreach and funding limitations, this is no longer a priority for the Advocacy Center. However, we remain committed to supporting the work of the DD Council in this area.*

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

**Activity 9.1.1** Advocate for

- policies that incentivize services for individualized integrated, competitive employment and dis-incentivize segregated, sheltered day habilitation services,
- 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.

*Advocacy Center staff continue to encourage and support OCDD's efforts to further implement and expand its Employment First plan. AC is hopeful that OCDD will devote the staff resources to ensure meaningful progress in this area. AC will serve on an OCDD stakeholder group to review the rates and services that are currently offered to better align services and support these efforts as much as possible.*

**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.

*The Advocacy Center serves on the Louisiana Rehabilitation Council (LRC.) The Council is looking at how other states go about drawing down VR federal dollars. Advocacy Center staff will work with the LRC to on this activity.*

**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.*