# Advocacy Center Quarterly Report to the DD Council

(April 2012)

# **Update/progress on agency initiatives**

1. When A House Is Not A Home: An investigation into conditions, care, and treatment in select group homes for people with intellectual disabilities in Louisiana

On March 20, 2012, the Advocacy Center issued a report on conditions in ICFs/DD (group homes) across the state. This investigation began after ombudsmen identified a clear pattern of neglect in specific group homes that was allowed to continue, despite repeated complaints and citations in facility surveys. These homes were selected because of problems that never seem to "get fixed" for long and are, in our opinion, the worst group homes in the state. It is clear that the state is not providing services in the most integrated setting possible, as required by federal law and that financial incentives keep group home providers from providing meaningful activities or employment opportunities in the community.

Advocacy Center ombudsmen will continue to work with the Department of Health and Hospitals to ensure quality of care in group homes will improve. Representative Walter Leger is planning to introduce a resolution to instruct the Department to investigate the use of sanctions for group homes.

### 2. Legislative Agenda

The Advocacy Center is addressing three major issues during this legislative session and appreciates the support of the Council.

- Mental Health Bill of Rights (HB 846) This initiative guarantees certain rights for people with mental illness which include the right to live in the most integrated setting appropriate, to participate in their treatment plans, to self direction, and to refuse treatment unless this creates a danger to self or others. The bill proposes a law that is very similar to the one in place for people with intellectual disabilities.
- Community Choice Waiver Slots In the 2012 Executive Budget, Governor
  Jindal funded 500 additional Community Choices Waiver (formerly the Elderly
  and Disabled Adult Waiver) slots in the Department of Health and Hospitals,
  Office of Aging and Adult Services budget. Over 25,000 people are waiting for
  this service, struggling to stay in their home without the assistance they need to
  avoid going into a nursing home.
- Bullying (HB 407/SB 619)— AC is working with a number of groups to support a bill to provide additional protections against bullying for students.

In addition to our monthly e-newsletter, *Pushing the Envelope: AC News in Brief*, we now have two email lists that will focus solely on policies and legislation.

**Policy Updates**: Throughout the year, Policy Update emails will update you on federal, state, and local policy decisions of note, including federal legislation, regulatory issues, policy debates, and other systemic issues that may impact people with disabilities and seniors in Louisiana. During the LA Legislative session (March 12 through June 4 in 2012), we will send regular updates summarizing major legislation. These emails will be informational only. They won't include a call to action.

**Take Action! AC Alert:** These emails are calls to action and will ask you to read about an issue and consider taking action by contacting elected officials or other policymakers. During the LA Legislative session, alerts will be sent several times a week, and maybe even several times a day. During the rest of the year, we'll send these alerts only to keep you informed about you how you can participate in federal, state, and local public policy issues.

Visit: http://advocacyla.org/index.php/newsletter-subscription.html to sign up.

AC has also introduced a section of our website dedicated to making it easier for you to Take Action and encourage your friends to do the same. http://takeaction.advocacyla.org

# 3. Home Nursing Services Issues

Advocacy Center staff initiated legal action on behalf of children who are being denied Medicaid home nursing services or whose hours are being reduced even though the children's conditions haven't improved. These decisions appear to be being made without proper notice regarding the reasons and without sufficient information about the child's needs (including whether family members are really available to meet their needs). Additionally, there are problems with the DHH contractor suggesting alternate services instead of home nursing without informing parents and doctors about the limitations of the alternate services.

If you know any Medicaid-eligible children (especially those on the NOW waiver waiting list) who have faced cuts in home nursing services, please encourage them to call the Advocacy Center.

### 4. LA Behavioral Health Partnership

Advocacy Center staff is monitoring the changes to the behavioral health services system and have been monitoring implementation of the program over the last few weeks. If you know of anyone who has encountered problems accessing behavioral health services, please ask him or her to contact the Advocacy Center.

#### 5. Accessible Taxicabs in New Orleans

Advocacy Center staff have been working with the New Orleans City Council to obtain approval for fully accessible taxicabs for the New Orleans area. Accessible taxicabs will be available beginning in early 2013.

## 6. Preparations for the 2012 Presidential Election

The Advocacy Center will be partnering with the Secretary of State to conduct outreaches regarding voting rights and demonstrations of accessible voting machines during Summer 2012. Contact the Advocacy Center if you are interested in training on voting rights and/or demonstrations at upcoming conferences and events. Staff will distribute more information on the events at the next Council meeting.

# 7. Advocacy Needed to Continue the WIPA (Work Incentives Planning Assistance) Program

The Advocacy Center and the Human Development Center jointly administer the WIPA program throughout the state of Louisiana. The WIPA program counsels Social Security beneficiaries who wish to work. Specially trained professionals help beneficiaries understand how they can return to work or begin work while, at the same time, retain important benefits they may need in order for them to be successful employees.

Unfortunately, the WIPA program is in trouble. Congressional authorization for the program will expire on June 30<sup>th</sup> Unless either Congress or the President acts, this would mean that, nationwide, we would have to lay off all the people who have been trained to give advice to SS beneficiaries and SS beneficiaries would have to rely on Social Security Administration employees for information on how employment and benefits interrelate. SSA employees have not been trained on the specifics of the relationship between employment and benefits.

If you care about losing this vital service for people with disabilities, please call your Congressman and ask that the WIPA program be reauthorized. You can also contact Kareem Dale Special Assistant to the President for Disability Policy <a href="mailto:kdale@who.eop.gov">kdale@who.eop.gov</a>.

### 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. See Item #1 above regarding the Advocacy Center's report into conditions at ICFs/DD. Further investigation and discussion of potential legal strategies is needed.

**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 continue to support the DD Council's efforts in this area.

**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.

Advocacy Center staff continue to outreach to parents of children with disabilities regarding the inappropriate use of restraint and seclusion. Staff welcome calls from parents on these issues.

In addition, staff have been working with the DD Council and other advocates regarding proposals for a voucher system for students in failing schools. These proposals are concerning as parents who choose to enroll their children in the voucher program forego their right to the protections provided by federal laws.

**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 work with members of the Employment First work group to implement these policies. Recent recommendations include training for support coordinators regarding employment options.

**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.

No action on this objective.

**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.

In 2011, Advocacy Center staff along with Louisiana Rehabilitation Services developed materials and conducted a number of trainings with sheltered workshop participants and their families regarding alternative employment options. Staff continue to work with group home advocates to promote access to a variety of employment options and to promote alternatives to sheltered workshops at outreaches and trainings.

### **New Initiatives**

In response to the Commissioner of the Administration on Developmental Disabilities, the Advocacy Center, the DDC and the HDC, among others, will be sending staff to a summit on Self Advocacy. It is hoped that this summit will breathe new life into the self -advocacy movement nationwide.