

Advocacy Center
Quarterly Report to the DD Council
(June 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 asked Medicaid for the opportunity to participate in stakeholder meetings, which are currently being scheduled. AC staff encourages all DD Council members to attend these meetings. Please contact us for more information about our concerns.

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, especially people living in institutions.

One success: The Advocacy Center represented a man who lived in a group home whose waiver offer was sent to an incorrect address in 2010. As a result of the mistake on the part of DHH, the man was removed from the Waiver Waiting List. He had been reinstated and told that he would get the next available offer, but after a year he was still waiting. AC drafted a complaint and presented it to DHH. Even though DHH maintained that they had "followed all their procedures", they finally relented and gave the man his Waiver and he can finally begin his newly independent life.

We are very concerned that with the Governor's veto of additional NOW slots, individuals on the waiting list will continue to be denied care in the most integrated setting appropriate to their needs.

3. Supported Independent Living Program Update

The Supported Independent Living Advocacy Project (SILAP), funded by the DD Council, serves people with developmental disabilities who live in the community with supports. The project has or is working with 13 people whose issues include: (1) freedom of choice among support agencies; (2) health/safety issues; (3) quality of support services; (4) lack of integration into the community; (5) need for money management support; (6) meaningful work, school or other appropriate daytime activities; (7) skills development.

The project, which is currently only working in Jefferson Parish, will extend its work into Orleans Parish within the coming weeks.

4. Emergency Management Disability & Aging Coalition Seeks Volunteers

The Advocacy Center, as a founding member and facilitator of the Emergency Management Disability & Aging Coalition (EMDAC) has worked tirelessly on many emergency management related issues, procedures, and guidelines.

With hurricane season upon us once again, we need your help to respond to the needs of people with disabilities and seniors in the event of an emergency. Volunteer manpower is desperately needed to assist with the collection and distribution of assistive technology devices before and after disasters.

To volunteer or for more information, contact Jeanne Abadie, AC Compliance Specialist, at 1-800-960-7705 x130 or jabadie@advocacyla.org OR Jamie Landry Karam at 1-800-270-6185 or jkaram@latan.org.

5. Priority Planning Survey: Tell Us What's Important To You

As you know, the mission of the Advocacy Center is to protect, empower, and advocate for the human and legal rights of people with disabilities and seniors living in Louisiana, in order that they may live an integrated life in the community, free from abuse, neglect, and exploitation.

We're asking people with disabilities, their families, and advocates to help set our agency's direction and priorities for the next three years.

Attached is a short priority planning survey was developed to make sure that people with disabilities, their families, and advocates have an opportunity to tell us what issues are most important to them. Please complete the survey and return it to Stephanie Patrick at the meeting or complete it online via the link below. Please share with others.

<https://docs.google.com/forms/d/1HBYVLq5Q6HK2-2oHX7hjeNZh5F1mZPa-Q5plmdWqBQU/viewform>

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

Access to Applied Behavioral Analysis for children on Medicaid is closer to becoming a reality. On May 21, the judge in the Chisholm lawsuit ruled that the state must immediately take steps to allow Board Certified Behavior Analysts to enroll as Medicaid providers and be able to bill Medicaid for necessary services to class members. Unfortunately, the state has appealed this decision and has filed a motion for a stay.

On June 19th, the Governor signed SB 134 into law, which will create a licensing

board and licensure regulations for Applied Behavioral Analysts. This is another important step in making sure Louisiana children are able to obtain this evidence-based therapy.

We are hopeful that Medicaid will begin funding this service for children who need it in the next few months.

7. Coordinated System of Care and Magellan

The Advocacy Center continues to examine the Coordinated System of Care (CSoC) in Louisiana to better understand how the system is working – or not working – for children and families. Children with developmental disabilities and mental illness who meet the other criteria for CSOC are supposed to be able to access CSOC services. If you or anyone you know has encountered problems attempting to access CSOC services, or with the type, quality, or amount of services they have received through CSOC or Magellan, please let us know.

8. Upcoming Elections

On October 19, 2013, many voters across the state will head to the polls to vote for local officials and on propositions. To find out if you vote in this election, visit www.geauxvote.com or contact the Advocacy Center. If you encounter any problems in registering or voting, Advocacy Center staff is happy to help. Call or email us.

9. Recent Successes

A gentleman in Lafayette who is visually impaired and has other medical conditions needed several lightweight musical instruments in order for him to work competitively in the music industry. He is a musician who specializes in Southwestern Louisiana musical styles. When the client first called the AC, he had already asked LRS (Louisiana Rehabilitation Services) for a Fair Hearing which he lost. The client's case was transferred to another LRS office. The client, with help from the Advocacy Center, requested an assistive technology evaluation for the lightweight musical instruments he needed to broaden his musical career. The evaluation clearly showed his need for the specialized musical equipment and it was purchased by LRS. Now that he has the instruments he needs, our client will be playing at a festival on the West Coast this summer and in Europe in the fall.

The mother of a child diagnosed with ADHD and autism contacted the Advocacy Center after her son was recommended for expulsion for bringing prohibited items to school. After speaking with the child and his mother and reviewing documents, an AC attorney attended the expulsion hearing. Following the presentation of the case, the Hearing Officer did not uphold the expulsion request. The child's behavior plan was modified to ensure that he would not inadvertently violate the rule on bringing

prohibited items to school. His mother agreed to this modification and he returned to school the next day.

The mother of a young child with ADHD, ODD and seizure disorder contacted the Advocacy Center for assistance getting her son evaluated for special education services. Due to his significant and multiple behavioral issues, she attempted to get this evaluation for several years, but was unsuccessful. The child was suspended several times and an expulsion hearing was pending. The school district had finally started the process for an evaluation just two weeks prior to the recommendation for expulsion. After reviewing documents and discussing the case with the child's mother, an AC attorney attended a hearing to determine if the child's behavior was related to his disability. The Hearing Officer found the child's behavior was related to his disability and accordingly the expulsion recommendation was not upheld.

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 supported the Disability Rights Rally and the DD Council's efforts to obtain additional waiver slots. AC will continue to collaborate with the Council on efforts to address the extensive waiting list and systems reform as needed.

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 continue to advocate for the needs of people with intellectual disabilities and mental illness with staff of the Office of Behavioral Health (OBH). Initial reports from families of individuals with intellectual disabilities and mental health issues indicate many are unaware of this resource. Staff recently provided OBH with a number of suggestions for outreach on this issue. Staff will continue to advocate on this issue and welcome reports of problems or difficulties accessing services.

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 supported the efforts of the Stop Bullying Coalition to introduce legislation requiring school districts to implement positive behavioral supports. This legislation was unsuccessful. We will continue to advocate in this area as resources permit.

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 continuing to survey group home residents on their current employment status, past history and employment goals. At this point, of the 1100 residents surveyed, less than 10% are in competitive employment, which is quite disappointing.

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. No new activities to report.

Protecting Your Rights:

Tell us what is important to you.

The mission of the Advocacy Center (AC) is to protect, empower and advocate for the human and legal rights of people with disabilities and seniors living in Louisiana, in order that they may live an integrated life in the community, free from abuse, neglect and exploitation.

AC is asking people with disabilities, their families and advocates, to help set the agency's direction and priorities for the next three years.

The following brief survey was developed to make sure that people with disabilities, their families, and advocates have an opportunity to tell us what issues are most important to them. Please answer for yourself, or for the person (people) you advocate for.

Please complete this survey and return it to:

Advocacy Center
8325 Oak St
New Orleans LA 70118-2043

Thank you for your help,
Dale Higgins, President of the Board
Lois Simpson, Executive Director
Advocacy Center

Please fill in the survey below.

I am (choose all that apply):

- Person with a disability
- Family member of a person with a disability
- Service provider
- Professional
- Advocate
- Age 60+
- Other _____

I am (choose all that apply):

- African American
- White
- Hispanic
- Native American
- Asian American
- Other _____

Your Parish: _____

Have you ever used AC services?

- Yes No

If you used services, were you satisfied with AC?

- Yes No

go to the next page →

The rest of the survey includes ten issue areas that may affect the lives of people with disabilities and seniors. Please tell AC the issues you think are the most important. On the survey, if an issue is not important to you, leave it blank. There is also space to write about any issues that are not included in the survey.

1. Community Integration. Is your life in the community limited by:

- Long Waiting Lists for Services and Supports
- Poor Quality Community Programs and Services
- Discrimination due to Disability
- Other _____

2. Housing. Is where you live limited by:

- Lack of Accessible Housing
- Lack of Funding to modify your Home
- Discrimination due to Disability or Age
- Other _____

3. Access. Is your physical access limited by:

- Inaccessible Commercial Buildings, (for example, Doctors' offices, restaurants, malls, theaters)
- Inaccessible Public Buildings or Recreation Areas, (for example, courthouses, state or city buildings, parks)
- Inaccessible Polling Places
- Inability to Access Assistive Technology Devices or Services
- Other _____

4. If you live in a facility, what kind of facility is it?

- Nursing Home
- State Hospital
- Private Hospital
- Pinecrest Developmental Center
- ICF/MR
- MR/DD Group Home
- Board and Care Home
- Facility for Children
- Other _____

5. Residential Facility. If you live in a facility, are you concerned about:

- Lack of Meaningful Choices, (for example, what to eat, have visitors, when to go out)
- Safety including Abuse or Neglect
- Use of Seclusion and Restraint
- Lack of Services
- Lack of Discharge Planning
- Lack of Employment Opportunities
- Other _____

6. Employment. Are you limited by:

- Discrimination in Hiring, Lay-Offs and Firings
- Failure to provide Reasonable Accommodations so you can do your Job
- Quality of Vocational Rehabilitation Services that will help you get a Job
- Lack of Information about how going to Work will affect your Benefits
- Denial of Access to Real Work (Having to Work in Sheltered Workshops or Day Habilitation Programs)
- Other _____

7. Healthcare. Are you affected by:

- Problems with Bayou Health Medicaid Managed Care
- Problems with Magellan Medicaid Managed Care
- Problems with Magellan Coordinated System of Care
- Problems with Traditional Medicaid
- Problems with Medicare
- Problems with/Lack of Mental Health Services
- Other _____

8. Education. Are your education or early intervention services limited by:

- Early Intervention not provided in Natural Environments (home, places in the community)
- Lack of Inclusion in Regular Classrooms
- Discipline, Suspension, Expulsion including Use of Seclusion and Restraint
- Transition – from Early Intervention to Preschool, Preschool to School-Age Programs and from School to Adult Life
- State Complaint Process (Due Process)
- Assistive Technology Devices or Services
- Extended School Year
- Individual Education Plan (IEP) Implementation Problems
- Access to Mental Health/Behavioral Health Services in School
- Other _____

9. Personal decision-making. Are your choices limited by:

- Restrictive Guardianships (Interdiction)
- Exploitation, Abuse or Neglect by a Guardian
- Exploitation, Abuse or Neglect by a Rep Payee
- Lack of Assistance with Advance Directives, (for example, living wills, power of attorney)
- Other _____

10. Describe other legal issues in your life that you are concerned about:

Enter your email address to sign up for: _____

- Partner With Us*
- Policy Updates*
- Pushing the Envelope: Advocacy Center News in Brief*
- Take Action! AC Alert*

Partner With Us: Want to find out about ways in which you can become involved with the Advocacy Center? Sign up for this email list! Throughout the year, we'll send emails about AC events, volunteer opportunities, and ways you can help spread awareness about our agency.

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, we will send regular updates summarizing major legislation. These emails will be informational only. They won't include a call to action.

Pushing the Envelope: Advocacy Center News in Brief: This is the Advocacy Center's free e-newsletter. It includes articles on issues impacting people with disabilities and seniors and the work of the Advocacy Center. It also includes a calendar of events and People of AC, which features AC staff. It is published monthly.

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.

To request help from the Advocacy Center, call 1-800-960-7705 (Voice or via 711 Relay) or email advocacycenter@advocacyla.org. Our Intake Specialist will contact you within 1-2 business days to discuss your issue in detail and determine if AC can help.

Thank you for filling out this survey. Your ideas are important to AC.

Return by mail to: Advocacy Center, 8325 Oak St, New Orleans LA 70118-2043
or email to advocacycenter@advocacyla.org.