

Advocacy Center
Quarterly Report to the DD Council
(September 24, 2013)

Update/progress on agency initiatives

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

As a result of an order in the Advocacy Center's *Chisholm* case, the Department of Health and Hospitals will arrange for ABA therapy by a board-certified ABA (BCBA) provider for any *Chisholm* class member for whom the services are medically necessary. DHH's enrollment process for BCBA's became available on September 11, 2013. The Department has established criteria for prior authorization and made arrangements for a clinician to provide service authorization recommendations to the Medicaid Behavioral Health Medical Director for final decision.

The *Chisholm* class includes Medicaid-eligible individuals under the age of 21 who are on the waiting list for the NOW waiver. The AC is asking class members or the caretakers of a class member who need of ABA services immediately, to please call Jeanne Abadie at 800-960-7705, ext. 130, or email her with the name of the caller, the name of the child, the caller's phone number and address, and the child's date of birth.

ABA therapy is also supposed to be available for children under the age of 3 through Early Steps. If anyone has problems getting these services, please call Jeanne Abadie at 800-960-7705, ext. 130.

2. Upcoming Elections

On October 19, 2013, many voters across the state will head to the polls to vote for local officials and on propositions.

In addition, voters in the 5th Congressional District will choose a replacement for Congressman Rodney Alexander. Parishes in the 5th Congressional District are all of Avoyelles, Caldwell, Catahoula, Concordia, East Carroll, Franklin, Grant, Jackson, LaSalle, Lincoln, Madison, Morehouse, Ouachita, Rapides, Richland, Tensas, Washington, West Carroll, West Feliciana and Winn. Parts of East Feliciana, St. Helena, St. Landry and Tangipahoa are also in the 5th Congressional District.

The Advocacy Center conducted a survey of candidates on disability issues including home and community based services, transportation, education and more. Responses are available at 5thCongress2013.advocacyla.org.

Also, on October 19th, the Advocacy Center will be staffing a voting hotline. Voters can call 1-800-960-7705 or email advocacycenter@advocacyla.org for answers to their voting questions or to complain about voting problems. The hotline will be open from 6 am to 8 pm.

3. 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 like group homes. We have identified a number of individuals who did not receive the proper notice about their waiver slot and a number have received a slot or been placed back on the waiting list with their original date of application. We welcome calls from people who are impacted by this issue.

4. Mental Health Services for People with Intellectual Disabilities

The Advocacy Center has concern that people with intellectual disabilities with mental or behavioral health issues and their families are not aware that they can access services through Magellan. The Office for Citizens with Developmental Disabilities is not the only resource for the families. We encourage families to call us if they are encountering difficulties accessing the mental or behavioral health services they need.

4. Changes in Eligibility for the Medicaid Purchase Plan

The Medicaid Purchase Plan (MPP) allows workers with disabilities to participate in the Medicaid program for their healthcare needs. The MPP is designed to be a true incentive for people with disabilities to work and earn a living wage without fear of losing their health insurance coverage.

People with countable income up to 250% of the federal poverty level can currently participate in the MPP program, with many paying a monthly premium to contribute to the cost of coverage. Spousal income is not counted. An individual can also have additional resources up to \$25,000. Many types of resources including retirement accounts and life insurance policies are not counted toward eligibility.

For 2014, Louisiana proposes: to lower the income eligibility level to no more than 100% of the federal poverty level (\$957.50 per month for a single person), to count spousal income; to limit additional resources to \$10,000 and to include retirement accounts, life insurance accounts, and medical savings accounts in the additional resource limit.

State officials justify the changes to the MPP ~~by saying~~ on the premise that those who are no longer eligible can receive coverage through Health Care Exchanges, created by the Affordable Care Act. While this coverage may be available to workers with disabilities, the premiums will cost between 2% and 8.05% of their income. In addition, out of pocket spending on co-pays and deductibles could cost \$2,000 or more per year. These costs are too high for people with disabilities who have expenses that a typical worker does not have. Additionally, these exchanges do not cover the cost of personal care services and other specialized medical needs.

The state estimates that 1,187 people will be impacted by the MPP's eligibility changes. At least 50 of those receive personal care services. The changes are scheduled to take effect on January 1, 2014.

If you or someone you know will be impacted by the new Medicaid Purchase Plan eligibility requirements, the Advocacy Center wants to hear from you. Please call Jeanne Abadie, Compliance Specialist, at 1-800-960-7705 x130 or jabadie@advocacyla.org.

5. Access to Interpreters in St. Tammany Parish Jails

The Advocacy Center recently investigated a complaint involving access to interpreters and communication devices for prisoners who are deaf or hard of hearing in St. Tammany jail. The staff at the jail agreed to improve access to these devices and to interpreter services. If you know of anyone who cannot access an interpreter or communication device at the jail, please contact the Advocacy Center.

6. Advocacy Center Southeast Louisiana Work Incentives Planning & Assistance (SELAWIPA) Accepting Referrals

The Advocacy Center is happy to announce the Social Security Administration funded Work Incentives Planning and Assistance (WIPA) program resumed providing FREE benefits advisement assistance to SSI and SSDI beneficiaries EFFECTIVE AUGUST 1, 2013. Certified Community Work Incentive Coordinators (CWICS) can assist clients understand the impact of work on SSA and other state and federal benefits. CWICS will develop an individualized benefits analysis plan that can be used as a guide to help clients achieve their employment goals.

Advocacy Center is authorized by SSA to provide benefits advisement services in the following Parishes: Orleans, Jefferson, East Baton Rouge, St. Tammany, St. Bernard, Plaquemines, Tangipahoa, West Feliciana, East Feliciana, St. Helena, Livingston, Ascension, Terrebonne, Ascension, Assumption, LaFourche, Washington, St. James, St. John the Baptist, and St. Charles.

To refer clients for WIPA services:

- Call Advocacy Center's SELAWIPA Intake at 1-855-877-8599 OR
- Complete an online WIPA referral form at www.work-pays.org

7. Executive Order - Improving State Employment for People with Disabilities

The Advocacy Center is working with disability advocates to encourage Governor Jindal to issue an Executive Order to increase the number of people with disabilities employed in state government to 7%. State Government has an important interest in reducing discrimination against Louisianians living with a disability, in eliminating the stigma associated with disability, and in encouraging Louisianians with disabilities to seek employment in the state workforce. As one of the State's largest employers, State Government must become a model for the employment of individuals with disabilities and executive departments and agencies must improve their efforts to employ workers with disabilities through increased recruitment, hiring,

and retention of these individuals. We hope that members of the DD Council will support these efforts.

8. Advocacy Center will train Affordable Care Act Navigators

The Advocacy Center will work with the Southwest Louisiana Health Education Center in Lafayette to ensure that Navigators under the ACA are well trained in terms of the needs of people with disabilities, especially potential needs for accommodations when interacting with the Navigators.

9. Increased Accessible in the French Quarter

In response to a request by the View Carre Property Owners Association, the Advocacy Center, with volunteer help from students at the LSU School of Rehabilitation Counseling, is conducting a survey of the entire French Quarter to note and record obstructions that make it impossible for users of wheelchairs to successfully navigate sidewalks. As an additional part of this project, the AC has received confirmation from the Regional Planning Commission that it will survey all sidewalks to identify sidewalks in need of repairs. The RPC will make repairs to sidewalks that are an impediment to people who use wheelchairs or who otherwise have mobility impairments.

10. Recent Successes

Medicare Appeal Results in Victory

One of AC's newest attorneys successfully represented a client in an appeal of a Medicare Advantage Plan's denial of a power seat elevation and power standing feature on her wheelchair. The client's existing power wheelchair could not be repaired, and she could no longer use the separate standing device because she lost her caregiver who helped her into the device. Her doctor and an independent assessor recommended that she have a wheelchair with features that would propel and hold her in a standing position.

The Medicare plan denied coverage for the elevation and standing features, citing a "Local Coverage Decision" that power standing features and power seat elevation systems are not covered by Medicare because they are "not primarily medical in nature."

The AC attorney represented the client at an administrative hearing, submitted extensive evidence and a post-hearing memorandum, and appeared at a supplemental hearing a month later. The judge held for our client, citing "overwhelming evidence showing that the features have been ordered for medical purposes." Our client is very pleased that she can finally get the assistive technology that she needs. We hope that this decision will be useful for others who need this kind of assistive technology from Medicare in the future.

Sweet freedom

One of AC's clients who has both cognitive and intellectual disabilities, was on probation and living in a group home. He was doing very well at the group home, receiving behavior supports and ongoing psychiatric treatment.

All this ended when he exhibited minor behavior issues at the home, causing his probation officer to resend his probation and send him back to jail. This was the start of his 2-week stint in lockdown at a parish prison without his medication. The AC attorney took action, discovering that although our client did have an extensive criminal history, he was not well represented by counsel throughout the years. He not only got the client out of jail but had charges from 2004 dismissed. The client was very grateful and gave his advocate a big hug when he was released.

Special Education Success

Two Advocacy Center attorneys filed a due process complaint on behalf of a high school student with mental illness who was denied his right to Special Education services and as a result, fell behind in school. Before the due process hearing occurred, a settlement meeting took place and the school district offered a monetary settlement to the parents to be used for tutoring and other educational services which are necessary to help this young man catch up in school. He and his parents are very pleased that he will finally get the special education services he's needed for a long time.

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.

Activity 3.1.4 Monitor the possible restructuring of long-term supports and services to a managed care system and advocate for an increased quality and quantity of services to be included in the reorganized system.

Activity 3.1.5 Research impact of managed care on individuals determined to be dual eligible and make recommendations to DHH.

Activity 3.1.6 Monitor the effect of Medicare/Medicaid dual eligibility on services for people with developmental disabilities.

The Advocacy Center continues to support the DD Council's efforts in this area. AC Staff is participating on the Managed Long Term Supports and Services workgroup and continues to advocate for the inclusion of institutional services and increased stakeholder involvement.

Objective 3.2 Admissions to residential facilities will decrease by increasing access to behavioral and medical intervention in the community and the discontinuation of people adjudicated into state-operated facilities.

Activity 3.2.1 Advocate in collaboration with the Advocacy Center for

- additional providers with specialized expertise in behavioral services;
- the development of plan upon admission that includes specific activities, persons responsible and timelines for discharge or transition; and
- improving the home and community based system by soliciting feedback from individual families using or trying to access behavioral health services and sharing that information with the DHH leadership.

Activity 3.2.2 Advocate for self-direction to be exempted from medication administration requirements.

Activity 3.2.3 Advocate for adequate rates that support services for people with complex medical and behavioral needs.

Advocacy Center staff continue to represent individuals with intellectual disabilities who are having difficulty accessing specialized services through the Louisiana Behavioral Health Partnership or Magellan. In a recent meeting with the Office of Behavioral Health, AC staff advocated for increased monitoring of the availability of specialized providers to meet the needs of these individuals. AC plans to continue these efforts.

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

- changes to the rate structure of the Residential Options Waiver to encourage private ICF/DD providers to convert their beds so individuals can transition to waiver services,

Activity 3.3.2 Advocate for initiatives that allow residents of private ICFs/DD to obtain waiver services.

The Advocacy Center continues to assist individual residents of ICF/DD to access waiver slots when appropriate. We are supportive of the state's efforts to increase utilization of the Residential Options waiver and continued funding of the ROW.

Objective 7.3 There will be an increase in the number of charter schools, early education programs, and other publically funded education facilities that approximate the percentage of students statewide served with developmental disabilities across all LEAs.

Activity 7.3.1 Advocate for improved oversight and monitoring of admissions and service delivery to students with disabilities in Charter Schools, early education programs, and other publicly funded education facilities in collaboration with the Advocacy Center.

The Advocacy Center's identified two special education priorities for Fiscal Year 2014. The first is exclusions from school including suspensions and expulsions and failure to identify and evaluate for special education services. The second is lack of appropriate transition services in schools. Advocacy Center staff welcomes calls from parents of children who are impacted by these issues.

Advocacy Center staff will continue to collaborate with the DD Council and LA TEACH to address systemic educational issues as resources permit.

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

Activity 7.4.1 Monitor and advocate as necessary against the use of 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.

This is not a systemic priority for the Advocacy Center at this time. However, we will investigate cases of inappropriate restraint and seclusion on behalf of students with disabilities and will support efforts of the DD Council and other advocates as resources permit.

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,
- LRS and OCDD will collaborate to mandate that all supported employment vendors/providers complete a university-based 40-hour training,
- Support family members and other advocates to serve on the Louisiana work team in developing an Employment First agenda and implementation plan including participation in state level meetings.

Advocacy Center staff continue to be concerned about efforts to complete and implement the OCDD Employment First plan as Employment First workgroup meetings are not scheduled on a consistent basis and are not productive when they are held. We hope that state officials will devote increased resources to this important effort.

With help from the CLOP program, AC is tracking approximately 115 individuals who expressed the desire to work. AC is also tracking clients who were found ineligible for LRS services and who are eligible for employment services under the Waiver programs. At least two clients have minimal progress in securing employment services under the Waiver and it seems clear that there is a need for

more education for support coordinators regarding the serviced and protocols to secure employment services under the NOW. AC is hopeful that the state will begin providing this training.

As part of AC's work on behalf of students who are transitioning, staff continues to advocate for increased involvement of Louisiana Rehabilitation Services. Staff is also advocating for increased training of supported employment vendors.

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 believes that Louisiana could benefit greatly from additional resources for Louisiana Rehabilitation Services and will continue to support efforts to increase LRS funding as resources allow.

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.

The Advocacy Center is addressing this initiative via the Employment First Initiative, WIPA benefits planning, and AC's new initiative to obtain an Executive Order to increase the number of people with disabilities in State jobs.