

Advocacy Center
Quarterly Report to the DD Council
(March 26, 2014)

Update/progress on agency initiatives

1. AC Files Lawsuit Regarding Access to Appropriate Notices

On March 18, 2014, the Advocacy Center filed a class action lawsuit on behalf of M. W., a 16-year-old girl with significant disabilities against the Department of Health and Hospitals. The lawsuit alleges that that LA Medicaid failed to provide notices to MW and her mother that gave them a meaningful opportunity to understand, review, and, when appropriate, challenge the Department's decision to cut MW's home nursing hours. Federal Medicaid law provides significant protections for recipients related to notices.

Stay tuned for updates.

2. 2014 Legislative Agenda

The Advocacy Center's legislative agenda is attached. We welcome collaboration with members of the DD Council.

3. Open Enrollment for Bayou Health Recipients

Each year, Bayou Health participants can change plans during open enrollment. Some individuals can also opt out and return to legacy Medicaid during this time. For people near Lafayette and in North LA, open enrollment is from April 1st to May 30th.

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

The Advocacy Center continues to monitor access to Applied Behavior Analysis (ABA) for children. In February, the state added ABA therapy to the Medicaid state plan, which means that any child will be able to access the service, as long as it is medically necessary.

The Louisiana Applied Behavior Analysis Board is now up and running, which is good because all ABA providers are required to be licensed in order to be able to bill Medicaid for ABA services.

If you or anyone you know is encountering problems in accessing ABA, please call Jeanne Abadie at 800-960-7705, ext. 130, or email her at jabadie@advocacyla.org 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.

5. 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 in

Orleans, Jefferson, Plaquemines and St. Bernard parishes. The project has or is working with 35 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. In addition to assisting people in these areas, SILAP is working with them to develop self-advocacy techniques as well as advocating for service delivery improvements for those receiving waiver services.

The Advocacy Center is now working to ensure that this program continues when DDC support is no longer available. Representative Leger will be championing an amendment to HB 1 to include funding to continue this program and expand it to the Baton Rouge area. Advocacy Center staff will be presenting testimony and letters of support to the Committee on April 14th and/or 15th.

6. APS Pro Bono Project

We had our first meeting in the Baton Rouge area last week. Several APS employees joined us in a meeting with the Baton Rouge Bar Association Pro Bono Project. We will be following up that meeting with a meeting with the Executive Director of South Louisiana Legal Services (which encompasses all of SE Louisiana) in that all pro bono cases have to be referred by SLLS. We have additional meetings scheduled with Keene Miller and Adams and Reese law firms in April.

10. Recent Successes

Matchmaker, matchmaker, make me a match...

RK has lived in an group home for over 20 years, always wishing for his own home in the community. The Advocacy Center ombudsman, who visits RK's group home, introduced R to JL in October 2013 at a local dance. She thought they would become friends because they both had a love for dancing.

J has a waiver, works at a fast food restaurant, and lives in the community with her family. The meeting with R changed her life. Not only did J fall in love with R, so did her family. On 2/14/14, R packed his belongings at the group home and moved in with J and her family. J's family cleared out a room in their home for R to call his own and committed to do whatever it took for him to live in the community until he finally gets his waiver. Less than 24 hours after he left the group home R proposed to J and they are getting married in April.

According to the AC ombudsman: "I know sometimes our jobs can be heartbreaking, challenging, and frustrating. I wanted to share this because sometimes something we do that seems insignificant at the time can change the life of someone we serve. I never thought a brief introduction would be the catalyst for creating a family. In October, R had no family, no hope of ever leaving a group home, and had never experienced the love and affection of a partner. Today he has a place to call home, a family, and a fiancé. This will be the best wedding ever."

Stay in School

The Advocacy Center assisted a 5 year old boy who was exhibiting aggressive behavior in his pre-K class, related to his Autism. The school threatened to send him to the alternative school against his parents' wishes. The attorney represented the child at a Manifestation Determination Review (MDR) with the mother . The MDR found that the child's behaviors were related to his disability and he therefore would not be sent to the alternative school. After an IEP meeting, the child's behavior goals were changed and the child's Behavior Intervention Plan (BIP) was revised. The child's behavior continues to improve.

Oh What a Relief It Is - not having to pay SSA back \$30,000!

In 2013, the Social Security Administration (SSA) wrote a nursing home resident to seek repayment of \$30,000 paid to her in 2011. The resident accurately reported her work history when applying for Social Security in 2011 and SSA recorded this information. The client was approved for Social Security and began receiving payments in 2011. Unbeknownst to the client, SSA based the payments on an incorrect last day of work. Although the client was unaware of how much she should receive, she did question whether the payments were correct by calling SSA twice in 2011. Both times, the client was assured the payments were correct. Two years later, SSA began seeking repayment, claiming they received "new information" about the client's work history. This so-called "new information" was the information that the client provided to SSA when she applied. An Advocacy Center attorney represented the client at an administrative hearing. Finding that the client was not at fault and that it would be inequitable to require her to pay back the \$30,000, the Administrative Law Judge waived the full amount of the claimed overpayment.

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 advocate for a managed care program for long-term services and supports that includes both institutional and home and community based services, provides for a robust complaint process and access to an ombudsman, and encourages meaningful stakeholder involvement. Staff also supported the Disability Rights Rally and legislative roundtables.

- 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 assist a number of individuals with intellectual disabilities and behavioral health needs to access community services via Magellan. We will continue to advocate for additional providers to meet the needs of this population, in collaboration with the DD Council. No additional progress to report.

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 is very concerned about OCDD's efforts to validate and assess individuals on the NOW waiting list. We hope that OCDD considers the rights of individuals with disabilities to direct their lives and services and protects their right to appeal. We continue to assist individuals living in group homes to access waiver services as we have discovered numerous problems with notifications and refusal of waiver services.

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.

Advocacy Center staff will continue to collaborate with the DD Council and LA TEACH to address systemic educational issues as resources permit. No additional progress to report.

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.

The Advocacy Center remains concerned about the slow pace of progress on the Employment First plan. We continue to advocate for increased employment options for people living in group homes and are currently following a number of individuals as they attempt to access services through Louisiana Rehabilitation Services. Staff are also addressing employment options as part of a focus on transition services in school. We are also advocating for an Executive Resolution to promote employment for people with disabilities in state government.

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 hopes to work with LRS staff and the Council to promote the benefits of LRS services.

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 continues to address this initiative via the Employment First Initiative, WIPA benefits planning, and AC's new initiative to increase the number of people with disabilities in state employment.



ADVOCACY CENTER
SERVING PEOPLE WITH DISABILITIES AND SENIOR CITIZENS

Legislative Priorities March 11, 2014

Highest Priority

SB355 by Senator Fred H. Mills, Jr.

FUNDS/FUNDING: Constitutional amendment to establish a budget stabilization program for Medicaid programs, certain elderly services, rehabilitation services, and other health care services.

Current Status: Pending Senate Finance
<https://www.legis.la.gov/legis/BillInfo.aspx?i=224544>

This Constitutional Amendment will give voters the opportunity to support protections for funding of critical services for people with disabilities and seniors in the November 2014 election. This protection is critical to ensure these services are funded in times of budget shortfalls, like much of the remainder of the budget.

The Advocacy Center is part of a large coalition of organizations supporting this bill.

HB 199 by Representative Austin Badon, Jr. and SB 164 by Senator Edwin R. Murray
DISCRIMINATION: Provides relative to discrimination

Current Status: Pending House Civil Law and Procedure
<https://www.legis.la.gov/legis/BillInfo.aspx?s=14RS&b=HB199&sbi=y>

Current Status: Pending Senate Judiciary A
<https://www.legis.la.gov/legis/BillInfo.aspx?s=14RS&b=SB164&sbi=y>

People with disabilities and seniors face discrimination in many aspects of their lives. House Bill 199 by Representative Badon and Senate Bill 164 by Senator Murray protect against this unjust discrimination in state laws.

The Advocacy Center is working with civil rights groups to support this legislation.

Funding for the SILAP Program

The Advocacy Center's Supported Independent Living Advocacy Program advocates for adults with developmental disabilities living independently in the community with supports to ensure they have an independent and high quality life, to empower individuals to

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The Protection and Advocacy System for Louisiana

advocate for themselves and act as independent and unbiased advocates when needed.

The SILAP program has been funded by the Developmental Disabilities Council since 2012. The Advocacy Center is advocating for funding to continue and expand this important program.

Home and Community Based Services

[SB 498](#) by Senator David Heitmeier

HEALTH CARE: Provides for personal care assistance services.

Current Status: Pending Senate Health and

Welfare <https://www.legis.la.gov/legis/BillInfo.aspx?s=14RS&b=SB498&sbi=y>

This legislation combines two programs which serve adults with disabilities, the State Personal Assistance Services and Community and Family Supports programs. This will increase administrative efficiency and provide opportunities for participants to obtain the personal care services or goods needed to maintain independence. The Advocacy Center supports this legislation.

[SB 499](#) by Senator David Heitmeier

HEALTH SERVICES: Provides for authorized procedures provided by direct service workers.

Current Status: Pending Senate Health and Welfare

<https://www.legis.la.gov/legis/BillInfo.aspx?s=14RS&b=SB499&sbi=y>

This legislation will allow direct services workers in home and community based services to administer insulin as part of the nurse delegation program. Many people with disabilities need regular insulin injections to maintain independence. The Advocacy Center supports this legislation.

Medicaid

There are a number of bills that support expansion of health insurance coverage for low-income individuals listed below. Many people with disabilities have low incomes and insurance coverage is vital to maintaining health. The Advocacy Center supports these bills.

- SB 77 by Senator Ben Nevers
- SB 96 by Senator Ben Nevers
- SB 107 by Senator Ben Nevers
- HB 174 by Representative Jared Brossett
- HB 240 by Representative Patricia Smith
- HB 261 by Representative Herbert B. Dixon

- HB 290 by Representative Patricia Smith
- HB 759 by Representative Barbara Norton

There are also a number of bills that prohibit expansion of health insurance benefits or implementation of the Affordable Care Act. The Advocacy Center opposes these bills.

- HB 335 by Representative Jerome “Dee” Richard
- HB 719 by Representative Paul Hollis
- HB 877 by Representative Paul Hollis
- HB 889 by Representative Paul Hollis

Visit <https://www.legis.la.gov/legis/BillSearch.aspx?sid=LAST> to view these bills.

HB 571 by Representative Julie Stokes and SB 349 by Senator J.P. Morrell
 MEDICAID: Provides relative to contracts for managed long term supports and services within the Medicaid program

Current Status: Pending House Health and Welfare
<https://www.legis.la.gov/legis/BillInfo.aspx?s=14RS&b=HB571&sbi=y>

Current Status: Pending Senate Health and Welfare
<https://www.legis.la.gov/legis/BillInfo.aspx?s=14RS&b=SB349&sbi=y>

These two pieces of legislation outline possible requirements that companies must meet to be considered to bid to provide managed long term supports and services in Louisiana. Many potential managed companies will be excluded from bidding to provide this vital service if this legislation passes. The Advocacy Center opposes both pieces of legislation.

Other Health

SB 541 by Senator Fred H. Mills, Jr.
 HEALTH CARE: Provides for the use of marijuana for medicinal purposes.

Current Status: Pending Senate Health and Welfare
<https://www.legis.la.gov/legis/BillInfo.aspx?s=14RS&b=SB541&sbi=y>

This legislation provides for procedures so that people with certain medical conditions can legally obtain medical marijuana.. The Advocacy Center supports this legislation.

HB 633 by Representative Regina Ashford Barrow
 INSURANCE/HEALTH: Provides relative to coverage of HIV/AIDS medications by health insurers

HB 704 by Representative John Bel Edwards
 INSURANCE/HEALTH: Requires health insurers to accept Ryan White funds in payment of premiums

Current Status: Pending House Insurance

<https://www.legis.la.gov/legis/BillInfo.aspx?s=14RS&b=HB633&sbi=y>

<https://www.legis.la.gov/legis/BillInfo.aspx?s=14RS&b=HB704&sbi=y>

People with HIV/AIDS have been unable to obtain health insurance through the private market because certain Louisiana insurance companies have restricted payments by third party payers. A number of people with HIV/AIDS receive assistance to pay insurance premiums from third parties. Both pieces of legislation above address this issue. The Advocacy Center supports both pieces of legislation.

SB 302 by Senator Fred H. Mills, Jr.

CIVIL PROCEDURE: Provides relative to medical consent and certain immunities.

Current Status: Pending Senate Judiciary A

<https://www.legis.la.gov/legis/BillInfo.aspx?s=14RS&b=SB302&sbi=y>

This bill expands doctors' authority to provide medical treatment when the patient is unable to consent and there is no one to consent on his or her behalf. The Advocacy Center understands there may be a need for additional MD authority, but have concerns about the breadth of this proposal and may propose additional protections. The Advocacy Center is not taking a position on the legislation at this time.

Education

HB 993 and HB 1015 by Representative John M. Schroder

EDUCATION/SPECIAL: Provides relative to requirements for pupil progression, graduation, and issuance of diplomas for students with exceptionalities

EDUCATION/SPECIAL: Provides for determinations for grade level promotion of certain students with exceptionalities regarding performance on state tests and prohibits test results of certain students from being used in school accountability calculations

Current Status: Pending House Education

<https://www.legis.la.gov/legis/BillInfo.aspx?s=14RS&b=HB993&sbi=y>

Current Status: Pending House Education

<https://www.legis.la.gov/legis/BillInfo.aspx?s=14RS&b=HB1015&sbi=y>

These bills provide that IEP teams determine grade level promotions, pupil progression, graduation requirements and diploma options for students with disabilities. The Advocacy Center supports these bills and will suggest amendments to increase clarity and specify that the school district bears the ultimate responsibility for these tasks.

Access

SB 432 by Senator Sherri Smith Buffington

HEALTH SERVICES: Provides relative to disabled persons and assistance dogs.

Current Status: Pending Senate Health and Welfare
<https://www.legis.la.gov/legis/BillInfo.aspx?i=224988>

This bill creates additional requirements for people with disabilities and their service animals. The requirements proposed SB 432 proposes are more restrictive than the Americans with Disabilities Act, the federal law that addresses service animals and the bill places undue burdens on individuals with disabilities who use service animals. In addition, the inconsistencies in federal and state law created by this bill may unnecessarily encumber individuals with disabilities visiting other states. The fact that a business owner may follow state law but still be found to violate federal law will also create confusion. The Advocacy Center opposes this bill as written.

Other Items of Concern

HB 63 by Representative Walt Leger, III
EXCEPTIONAL PERSONS: Revises terminology referring to persons with disabilities and other persons with exceptionalities

Current Status: Pending House Health and Welfare
<https://www.legis.la.gov/legis/BillInfo.aspx?i=223684>

This bill removes inappropriate terminology used to describe people with disabilities through the Louisiana Revised Statutes and replaces it with People First language, which is preferred by the disability community. It does not make substantive changes to the law. The Advocacy Center supports this bill.

HB 833 by Representative Franklin J. Foil
EXCEPTIONAL PERSONS: Creates the ABLE Account savings program for persons with significant disabilities

Current Status: Pending House Health and Welfare
<https://www.legis.la.gov/legis/BillInfo.aspx?s=14RS&b=HB833&sbi=y>

This bill creates a saving plan for people with disabilities similar to those used for college savings. The funds are required to be used for disability-related expenses and may be shielded from taxes. Legislation is pending in the US Congress to protect such funds from federal taxation and consideration as resources in Medicaid eligibility determinations. Even if the federal legislation passes, however, the funds will count as resources against SSI payments. This, and the fact that until the federal legislation passes these funds will count as resources in Medicaid eligibility determinations, raises concerns regarding the appropriateness of such plans many people with disabilities. On the other hand, increasing the options to save for disability related costs can improve the lives of people with disabilities. The Advocacy Center supports this bill but encourages people with disabilities to be fully informed as to its effects before creating such accounts.

HB 612 by Representative Neil Abramson
CIVIL/ACTIONS: Provides relative to class actions

Current Status: Pending House Civil Law and Procedure

<https://www.legis.la.gov/legis/BillInfo.aspx?s=14RS&b=HB612&sbi=y>

This bill restricts class actions, a type of lawsuit involving group of people. The Advocacy Center believes that class actions are an efficient and effective way of resolving systemic problems and that the management of class actions should be left to the judiciary. The Advocacy Center opposes this bill.

HB 142 by Representative Jerome "Dee" Richard

PUBLIC CONTRACTS: Provides for a 10% reduction of all state professional, personal, and consulting service contracts and provides for deposit of the savings into the Higher Education Financing Fund

Current Status: Pending House Appropriations

<https://www.legis.la.gov/legis/BillInfo.aspx?s=14RS&b=HB142&sbi=y>

This bill calls for a 10% reduction of all state contracts in certain categories. The Advocacy Center believes that broad cuts are not the most effective way to insure efficient services and opposes this bill.

If you have questions about the Advocacy Center's 2014 Legislative Agenda, contact Stephanie Patrick at 1-800-960-7705, ext 143 or spatrick@advocacyla.org.

Take Action

The Advocacy Center's "Take Action! AC Alerts" are call-to-action emails that ask you to contact elected officials or policymakers about legislative issues. Visit <http://advocacyla.org/index.php/newsletter-subscription.html> to subscribe today!