

Advocacy Center
Quarterly Report to the DD Council
(June 25, 2014)

Update/progress on agency initiatives

1. Legislative Update

The Advocacy Center focused on three major legislative initiatives during the 2014 session. The first, to protect funding for critical services for people with disabilities in collaboration with the DD Council, AARP and a number of other groups, failed. The second, to provide additional protections to seniors, people with disabilities and other vulnerable groups, also failed. However, we continue to support these important initiatives and will address them in the future.

The third initiative was to obtain funding for the Advocacy Center's Supported Independent Living Advocacy Program. This program was established and funded for two years through the support of the DD Council. The Advocacy Center obtained funding to continue the program in the New Orleans area and expand to serve people in the Baton Rouge area too. The program will be administered by the Office of the Attorney General.

In addition, below are a few other pieces of legislation that received less attention during the session but have the potential to address significant needs of people with disabilities.

[SB 432](#) by Senator Sherri Smith Buffington
HEALTH SERVICES: Provides relative to disabled persons and assistance dogs.

<https://www.legis.la.gov/legis/BillInfo.aspx?i=224988>

This bill creates additional requirements for people with disabilities and their service animals. Originally the requirements proposed in SB 432 were more restrictive than in the Americans with Disabilities Act, the federal law that addresses service animals. The bill would have placed undue burdens on individuals with disabilities who use service animals. In addition, the original bill created inconsistencies in federal and state law that would have unnecessarily encumbered individuals with disabilities visiting from other states. The fact that a business owner may follow state law but still be found to violate federal law would have also created confusion. The Advocacy Center opposed this bill as originally written.

This bill was amended to address all the Advocacy Center's concerns and to ensure compliance with the ADA. We appreciate the support of Deshae Lott and other members of the DD Council as we advocated for amendments to the bill to ensure consistency with the ADA. The bill was signed by the Governor and is now Act 492. The Advocacy Center is hoping to work with legislators to increase awareness of service animals among business owners in the next few months.

[SB 302](#) by Senator Fred H. Mills, Jr.
CIVIL PROCEDURE: Provides relative to medical consent and certain immunities.

<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 recognized the need for additional MD authority, but initially had concerns about the breadth of this proposal and lack of protections. Thanks to Senator Mills and the bill's supporters, this bill was amended to address all the Advocacy Center's concerns and we supported it.

The bill has been signed by the Governor and is now Act 601.

SB 682 by Senator Ben Nevers

HEALTH CARE: Provides for the Louisiana First America Next Freedom and Empowerment Plan.

<http://www.legis.la.gov/legis/BillInfo.aspx?s=14RS&b=SB682&sbi=y>

The bill, introduced by Senator Nevers as an alternative to Medicaid expansion, reflects many of the concepts outlined in the Governor's America Next plan (<http://americanxt.org/wp-content/uploads/2014/04/The-Freedom-and-Empowerment-Plan.pdf>). It directs the LA Department of Health and Hospitals to study the concepts outlined in the legislation and develop a plan for implementation. The plan must be approved by the Joint Legislative Committee on the budget prior to implementation.

The bill has been signed by the Governor and is Act 783. The Advocacy Center will closely monitor its implementation to ensure there are no negative impacts on people with disabilities.

2. Waiver Participants and Bayou Health

The Advocacy Center is pleased that the Department of Health and Hospitals is planning to give waiver participants the option to sign up for Bayou Health beginning on July 1st, 2014. However, we are concerned that individuals may not be fully informed about the benefits and risks of this move.

We will be distributing further information about the potential risks and benefits of signing up to participate in Bayou Health via our newsletter in the next few weeks and will distribute it via hard copy at the DD Council meeting.

We also hope to speak to members of the Council about this issue at the July meeting.

3. Preparing for the November Congressional Election

On Tuesday, November 4th, 2014, Louisiana voters will head to the polls to elect US Representatives and one US Senator.

Leading up to the election, we will be coordinating a number of activities to help LA voters prepare:

- Survey of the Candidates
- Series of newsletter articles on voting issues
- Outreach to people in institutions
- Training for people with disabilities
- Collaboration with other groups and organizations

If you have suggestions or ideas about how to educate people with disabilities about their voting rights or other things we can do, please let us know.

7. Update – Promoting Employment for People with Disabilities

The Advocacy Center is convening a coalition to discuss ways to promote employment for people with disabilities during Disability Employment Awareness month in October and beyond.

We are hopeful that the coalition will discuss opportunities to promote employment via outreaches, trainings, media, public policy and legislative actions. The first meeting will be held on June 24th.

We are pleased that the DD Council will be participating and welcome feedback and suggestions from Council members.

8. Supported Independent Living Program Update

We continue to accept cases in the Human Services Districts for greater N.O. and Jefferson and are making plans to expand the program to the greater Baton Rouge area. We are in the process of negotiating a contract with the AG's Office, which will fund the project when DD Council funding terminates. We will be hiring at least one additional full time person for the program once we have a fully executed contract with the State.

9. APS Pro Bono Project Update

At this point in the project, the AC has met with four of the largest law firms in the state, all based in either New Orleans or Baton Rouge. They all expressed interest in the program and requested further presentations and meetings to more fully inform members of the firms. We will present a program, more fully explaining the project and pitching for volunteers, to members of these firms during the summer.

We have also met with Pro Bono Projects in Baton Rouge and New Orleans. We learned that the Pro Bono Projects only take referrals from the Legal Services Corporations. Thus, our next step was to meet with the Director of the South East Louisiana Legal Service Corporation. She, in turn, met with the other two LSC Directors. They are not interested in accepting APS cases, so that proved to be a bit of a dead end.

We are moving ahead with the development of a series of video training programs on APS cases, which we hope will attract attorneys to take APS cases. The videos will carry Continuing Legal Education credits.

Finally, we have attempted to schedule meetings with firms in the northern part of the state but have found that none of them has a pro bono component to their firm. Thus, it would be unproductive to travel there to explain the program to them.

10. Recent Successes

Access to Nursing Care Helps Child Stay at Home

R, a 12-year-old boy suffered a brain injury after he collapsed while playing baseball, was discharged from the hospital with 48 hours of Medicaid funded home nursing care. His father, Mr. K called the Advocacy Center for help when R's nursing hours were terminated a few months later, without any evidence that R's condition had improved. Mr. K was desperate. He did not know how he could keep R at home without this vital support.

R is a part of the Advocacy Center's Chisholm lawsuit, which protects the rights of children aged 3 to 21 who are on the New Opportunities waiting list. The Advocacy Center attorney wrote a letter pointing out violations of the Chisholm orders, and R's hours were immediately reinstated. In addition, DHH is making systemic changes to prevent this violation from happening in the future.

WIPA Helps KR Continue Working Fulltime

LC, a young man with significant disabilities, contact the Advocacy Center's WIPA program for help, after he received a letter from Social Security (SSA) telling him that he was no longer eligible for SSDI disability payments. LC didn't know what to do and was scared. His first reaction was to cut his work hours in half in order to keep his Social Security check.

His WIPA advocate met with him and explained that cutting work hours might not be necessary and agreed to investigate. First, she did a comprehensive benefit assessment, reviewing his living expenses, employment situation and the status of his health insurance, pharmacy claims etc. The WIPA advocate then helped Mr. C submit proof of Impairment Related Work Expenses (IRWE's) to SSA.

Next, his WIPA advocate helped him draft a letter to the SSA Area Work Incentives Coordinator (AWIC) requesting that she re-review his pay stubs which showed that he took paid time off on several dates. The WIPA advocate also requested the AWIC apply a subsidy that would allow Mr. C to use the supports he receives on the job as a work incentive. The AWIC agreed to the request and mailed a Work Activity Questionnaire to Mr. C's work supervisor. SSA made a decision to apply the work incentives recommended by Mr. C's WIPA advocate.

As a result of WIPA's advice on the work incentives, Mr. C will continue to receive his SSDI. He did not have to reduce his work hours and happily continues to work full-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 participate in stakeholder meetings regarding the possible transition to managed care for long term services and supports. We recently sent a letter to the Department of Health and Hospitals outlining a number of concerns, focusing on potential issues for people with adult onset disabilities and in nursing homes. The letter is available at: <http://advocacyla.org/index.php/news-reader/items/state-moves-toward-managed-care-for-long-term-services-and-supports.html>.

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 individuals with intellectual disabilities and behavioral health needs to access community services via Magellan. In particular, we have been working with the Department of Health and Hospitals to expand access to therapeutic foster care. We welcome additional collaboration with the DD Council and suggestions on how to address this important issue.

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 hopeful that the additional resources for waiver services at outlined in the HB 1 will mean that the state will begin offering NOW waiver slots again. However, we remain concerned about the long waiting time and the state's efforts to manage the list.

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.

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 and we have not received any complaints about this issue from parents of students with disabilities. However, we will consider investigations of inappropriate restraint and seclusion 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. As noted above, we are hoping to convene a coalition to promote employment of people with disabilities as a way to promote employment outside of the Employment First initiative.

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 is pleased that potential cuts to Louisiana Rehabilitation Services were addressed during the legislative session and we are hopeful that this will allow LRS to open additional Orders of Selection. We 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 continues to address this initiative via the Employment First Initiative, WIPA benefits planning, and AC's initiative to monitor and promote employment opportunities for people in group homes.

Quarterly Discussion: Early Intervention

What that agency is currently doing and/or planning to do to achieve the desired goal/outcome?

- Access Medicaid Funded Services – The Advocacy Center provides assistance to many young children with significant disabilities who need Medicaid funded services to remain home. Recent issues have included access to home nursing services and proper notices. Children with disabilities who are ages 3-21 and on the NOW waiting list are also covered under the Chisholm lawsuit, which provides for a number of special legal protections.
- Access to Early Steps – Due to limited resources, access to services via Early Steps is not a priority of the Advocacy Center. We have not received complaints about problems with Early Steps in recent years and it has not been identified as a high priority in comments from the public, but we could consider systemic advocacy if needed.
- Access to Services for Children with Mental Illnesses – Since the state cut funding for the Early Childhood Supports and Services program and decided that these children were to be served under the Coordinated System of Care, the Advocacy Center has been concerned about whether these services are meeting the needs of these children. However, we have not received any complaints. We welcome collaboration with the DD Council if there are issues.
- Access to Services for Children with Autism – The state recently added Applied Behavioral Analysis therapy as a state plan service, meaning that it should be available to young children. The Advocacy Center is closely monitoring access to ABA therapy and welcomes information about problems or barriers.
- Access to Day Care – Again, due to limited resources, the Advocacy Center has not prioritized access to accessible day care for children with disabilities. We have not received complaints in this area.

What the agency would like to do to achieve the desired goal/outcome but specify barriers preventing this activity

As noted above, due to limited resources, the Advocacy Center has not investigated or addressed the quality of services from Early Steps or access to accessible day cares. This is primarily due to a lack of resources and lack of complaints from individuals.