

Advocacy Center
Quarterly Report to the DD Council
(June 23, 2015)

Update/progress on agency initiatives

1. Update on Supported Independent Living Advocacy Project

The Advocacy Center is excited to announce that the legislature restored funding to continue the Supported Independent Living Advocacy Project for an additional year. The program serves people receiving NOW services in the greater New Orleans and Baton Rouge areas.

SILAP success story:

A few months ago, SILAP Program Director was contacted by a support coordination agency in the regarding possible financial exploitation of a Ms. M by her representative payee, a family member. SILAP met with Ms. M who said she was afraid of her representative payee and wanted someone else to handle her money. Just as the SILAP staff member was beginning the investigation, Ms. M's home situation became very unsafe. Very quickly, a team (made up of SILAP, APS, CAHSD, and providers) was assembled and plans began were made to ensure Ms. M's safety. With the help of her SILAP coordinator and team, Ms. M quickly move to a respite facility and then to an SIL apartment. She is happy and is enjoying more independence. A new representative payee has been appointed and she is able to spend her money as she chooses.

2. Lawsuit Filed Against Angola Prison and Louisiana Department of Public Safety and Corrections Over Unconstitutional and Deficient Medical Care

Prisoners at the Louisiana State Penitentiary at Angola (Angola) filed a lawsuit last month alleging that they needlessly suffer from chronic pain, permanent injury, and preventable sickness and death as a result of prison officials' failure to provide constitutionally adequate medical care.

The Advocacy Center (AC), the American Civil Liberties Union Foundation of Louisiana (ACLU-La), the law firm Cohen Milstein Sellers & Toll PLLC (Cohen Milstein), and the Promise of Justice Initiative (PJI) filed a complaint against the Louisiana Department of Public Safety and Corrections (DOC) and Angola's wardens alleging violations of the Cruel and Unusual Punishment clause of the Eighth Amendment and federal disability statutes. The complaint, titled *Lewis et al. v. Cain et al.*, was filed in the U.S. District Court for the Middle District of Louisiana. In challenging the inadequate medical care, the complaint alleges that the prison's more than 6,000 prisoners are all at risk of serious harm, while scores of men have already experienced unnecessary injury, suffering and death.

The class action complaint details several problem areas at the prison: delays in evaluation, treatment, and access to specialty care; denial of medically necessary

treatments including surgeries, medication, medical devices, and physical therapy; inappropriately managed medications; poor follow-up care; and a lack of qualified staff. The complaint also details the way these medical problems impose hardship on prisoners in other areas such as work duties and housing assignments.

Prisoners report horror story after horror story: a man denied access to a specialist for four years while his throat cancer advanced; a man denied medical attention four times during a stroke, which left him blind and paralyzed; a blind man denied even a cane for 16 years. In many cases, only the specter of legal action spurred the prison to provide long-delayed medical care.

The complaint contends that Angola's medical care worsened when Earl K. Long Hospital in Baton Rouge, which used to serve prisoners with medical emergencies, was closed during the reorganization of the state's Charity Hospital System. Even basic screenings and treatments are now being broadly denied.

"The grave systemic deficiencies in the delivery of medical care at Angola lead to appalling outcomes," said Jeffrey Dubner, Associate at Cohen Milstein. "Preventable illness, injury and death are not part of a prison sentence, yet Angola officials are pervasively subjecting the men in their custody to these risks."

The complaint also alleges that disabled prisoners are especially hard-hit by the inadequate delivery of care. Miranda Tait, Managing Attorney for AC, said, "Because prisoners with disabilities generally require stabilizing care and management of chronic conditions, the failure of the prison to deliver adequate care heightens the chance that a prisoner with disabilities will be condemned to increased misery and exacerbated disabilities."

The investigation into the delivery of medical care at Angola began more than two years ago as a result of multiple prisoners' reports of grossly inadequate medical care. Attorneys interviewed more than 200 men in connection with this investigation and found scores whose problems echo those of the plaintiffs named in the complaint. The class action seeks an injunction that will bring the prison in line with constitutional standards in the delivery of medical care.

3. Preparing for the Gubernatorial Election – Know Your Rights

Are you interested in learning more about voting rights in preparation for the October 24 election? Advocacy Center staff can provide online and in person training on a number of topics, including:

- Voting rights of people with disabilities
- Why voting is important
- How to register to vote
- Assistance in voting
- Working as a poll worker
- Polling place accessibility

Staff can also draft articles for inclusion in your newsletter or on your website.

To request a training or for more information, contact Stephanie Patrick at 504-522-2337, ext. 143 or spatrick@advocacyla.org.

4. National Disability Rights Network Releases *Orphanages, Training Schools, Reform Schools and Now This?*

“More than 65 percent of youth in the justice system meet the criteria for a disability, a rate that is three times higher than that of the general population,” said Curt Decker, NDRN’s executive director. “The millions we spend housing and feeding our young people behind razor wire can be far better spent helping them to find their way in this world.”

Issues addressed in this report include: Diversion of children and youth with disabilities from the juvenile justice system (particularly stemming the “School to Prison Pipeline”), provision of humane conditions while incarcerated (such as accommodation and communication needs, medical care, mental health treatment, and the prevention of abuse and neglect) and re-entry services like education and treatment to ensure the child or youth’s success upon release from the facility.

The report describes the problems children and youth with disabilities encounter, solutions used with success by the P&As, and provides specific recommendations for systemic improvements.

Some of those recommendations include:

- Congress should authorize and fund a Protection and Advocacy for Juvenile Justice Program to help divert youth with disabilities from entering the juvenile justice system, investigate and monitor conditions for youth with disabilities in the juvenile justice system, and ensure proper return to the community with needed services and supports.
- Congress should prohibit the use of solitary confinement and/or isolation for all juveniles, including those housed in adult settings.
- Congress should require that schools identified as having elevated school-based arrest rates: 1) lose the opportunity to use federal funds to employ School Resource Officers (SROs); 2) ensure SROs work is limited to traditional police activities and not discipline of non-violent student behavior; and, 3) require SROs in those schools to undergo training in specific, related topics.
- The U.S. Department of Education (ED) and Department of Justice (DOJ) should fully enforce laws requiring that education of youth in facilities is equal to that provided to students in other public schools.

Read the full report at:

http://ndrn.org/images/Documents/Issues/Juvenile_Justice/NDRN_-_Juvenile_Justice_Report.pdf

5. LA Plans Changes to Behavioral Health Service System

In November 2014, the Department of Health and Hospitals announced a major shift in how Medicaid funded specialized behavioral health services will be provided. Since March of 2012, these services have been managed by Magellan of Louisiana. Beginning on December 1, 2015, these services will instead be provided by the Bayou Health managed care companies that currently provide services for primary and acute care.

The Advocacy Center's PAIMI Advisory Council has been monitoring this transition and is concerned that there are significant gap in the state's plan. It sent a letter to Secretary Kliebert outlining the Council's concerns regarding the involvement of consumers in the planning process, the need for truly integrated services, the importance of a smooth transition and the preservation of services, and the responsibility of the Bayou Health companies to address the gaps in certain services, like respite and crisis stabilization.

At a meeting with providers, consumers, and advocates on April 29, 2015, DHH provided the following timeline for implementation:

- August 1, 2015 – Finalized Bayou Health contract amendment
- September/October, 2015 – DHH readiness review of MCOs
- September/October, 2015 – Open enrollment begins
- December 1, 2015 – Integration go-live

DHH also announced plans to move forward with several positive changes. "Crisis Stabilization" (a service providing out-of-home care for children and youth in crisis for periods of up to 7 days) will be made available to all Medicaid eligible youth who need it. Right now, this service is only available to youth who have been approved to receive services through the Coordinated System of Care ("CSOC").

Additionally, DHH will expand the availability of providers for short-term respite services (respite care for up to 72 hours) for CSOC participants by allowing Therapeutic Foster Care providers to provide short-term respite services for CSOC recipients. DHH is also planning to include Therapeutic Foster Care in the State Plan as a Medicaid covered service.

6. Bayou Health Expands to Include Chisholm Class Members

Beginning this Spring, children in Louisiana between the ages of 3 and 21 who are on the NOW waiting list (Chisholm class members*) became able to get Medicaid services through Bayou Health.

It is important that individuals and their families look closely at the potential benefits and risks of enrolling in Bayou Health.

Bayou Health is the state's managed care program for Medicaid recipients. Five private companies contract with the state to manage the acute health needs of

individuals who are enrolled. Some of these health plans have a different network of doctors, hospitals, and other providers than traditional Medicaid.

Benefits of enrolling in Bayou Health may include access to a different set of medical providers. In addition, some plans offer incentives for successfully meeting certain outcomes.

To learn more about the specific benefits that each plan offers, visit https://bayouhealth.com/LASelfService/en_US/pdfs/LA-BenefitsCompChartOE.pdf.

There are also significant risks in moving to managed care. Some potential issues include:

- Access to your current doctors and other healthcare providers. Not all doctors and healthcare providers are enrolled in all the managed care plans. If you want to keep your doctors, it's important to confirm that they are all enrolled in the plan you choose.
- Access to services. The managed care company will be determining the types, amounts, and duration of services to be received. The Advocacy Center has assisted a number of individuals who have encountered problems in getting needed services approved by plans in a timely manner or whose services have been reduced significantly.
- Access to prescription medications. Each plan covers different drugs and has different prior authorization and step therapy procedures. It's important to check that you can access needed medications on the new plan.
 - Aetna Better Health: <http://www.aetnabetterhealth.com/louisiana/providers/pharmacy>
 - LA Healthcare Connections: <http://www.louisianahealthconnect.com/for-members/pharmacy-services>
 - Amerihealth Caritas: <http://www.amerihealthcaritasla.com/pharmacy/index.aspx>
 - Amerigroup: <https://www.myamerigroup.com/LA/Pages/medicaid.aspx>
 - UnitedHealthcare: <http://www.uhccommunityplan.com/la/medicaid/bayou-health/find-a-drug.html>
 - Legacy Medicaid: http://www.lamedicaid.com/provweb1/forms/rxpa/PDL_and_NPDL_%201-1-14.pdf

If a Chisholm class member joins Bayou Health and encounters problems, he or she can request to return to traditional Medicaid. The change will go into effect the 1st of the month following the request. Class members may be required to resubmit requests or prescriptions to the new plan. If a class member decided to go back to Bayou Health, he or she would have to wait until the next open enrollment period.

Children do not become Chisholm class members until they are 3 years old because that is when they can be placed on the NOW waiting list through OCDD or their local human services district. They may have a "protected Registry date" prior to age 3, but

until they are formally found eligible for the DD services system, they are not Chisholm class members.

Individuals who are currently enrolled in Bayou Health and are placed on the NOW waiting list become Chisholm class members. At that point, they have the option to return to legacy Medicaid or remain with Bayou Health.

To enroll or dis-enroll in Bayou Health, call 1-855-BAYOU-4U (1-855-229-6848) or TTY: 1-855-LAMed4Me (1-855-526-3346).

If you have any questions about this, or if you encounter problems accessing services under Bayou Health, contact the Advocacy Center at 1-800-960-7705.

* Chisholm v. Kliebert, a class action lawsuit filed by the Advocacy Center in 1997, resulted in the state providing necessary services under regular Medicaid to children on the New Opportunities Waiver (NOW) waiting list. Chisholm class members are children up to age 21 who currently receive or are eligible for Medicaid, and who are on the NOW waiting list.

7. Medicaid application processing time

The Department of Health and Hospitals is not meeting federal Medicaid requirements regarding application processing times. For applications where Medicaid must assess disability, federal regulations require the Medicaid agency to determine eligibility and send applicants notice of whether they are eligible within 90 days of the date they apply. For people who do not need a disability assessment, the time limit is 45 days. David Williams, an attorney working with the Advocacy Center, has recently sent a public records act request and gotten a response showing that a very large percentage of the eligibility determinations are not being made timely.

If anyone knows of people affected by this (not being able to get an answer on Medicaid eligibility in 45 days--90 days if a disability determination had not been made prior to applying), please have them contact the Advocacy Center, 800-960-7705.

8. Accommodations for people with communications disabilities:

The Advocacy Center is concerned about how the Department of Health and Hospitals and the Division of Administrative Law insure that their communications with people with disabilities are as effective as those with people without disabilities.

The Americans with Disabilities Act, 42 U.S.C. §12132, prohibits public entities from excluding individuals from their programs by reason of disability. The regulations implementing Title II of the ADA provide that “[a] public entity shall take appropriate steps to ensure that communications with applicants, participants, members of the public, and companions with disabilities are as effective as communications with others.” This includes furnishing appropriate “auxiliary aids and services” where necessary to provide applicants, participants, companions, and members of the public

an equal opportunity to participate in, and enjoy the benefits of the public entity's services and programs.

"Auxiliary aids and services" include—

- (1) Qualified interpreters on-site or through video remote interpreting (VRI) services; notetakers; real-time computer-aided transcription services; written materials; exchange of written notes; telephone handset amplifiers; assistive listening devices; assistive listening systems; telephones compatible with hearing aids; closed caption decoders; open and closed captioning, including real-time captioning; voice, text, and video-based telecommunications products and systems, including text telephones (TTYs), videophones, and captioned telephones, or equally effective telecommunications devices; videotext displays; accessible electronic and information technology; or other effective methods of making aurally delivered information available to individuals who are deaf or hard of hearing;
- (2) Qualified readers; taped texts; audio recordings; Brailled materials and displays; screen reader software; magnification software; optical readers; secondary auditory programs (SAP); large print materials; accessible electronic and information technology; or other effective methods of making visually delivered materials available to individuals who are blind or have low vision;
- (3) Acquisition or modification of equipment or devices; and
- (4) Other similar services and actions.

It has recently come to our attention, especially in the application process for Long Term Personal Care services, that DHH has not adopted policies that insure effective communication for people with visual impairments. Further, the Division of Administrative Law does not have effective policies for providing communication access for people with visual disabilities in connection with the appeals of any denials.

If anyone knows of people whose disabilities have hampered communication with DHH or DAL, please have them contact the Advocacy Center, 800-960-7705.

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.

While the Advocacy Center is pleased that the legislature funded a limited number of NOW slots for Fiscal Year 2015-2016, we are concerned that most Community Choices waiver slots, also used by individuals with developmental disabilities, remain frozen. Staff will continue to advocate for increased waiver services in individual cases and on a systemic level.

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.

As the state continues to delay the move toward managed long term services and supports, the Advocacy Center remains concerned that individuals receiving waiver services and Chisholm class members will be forced to move to Bayou Health to access behavioral health services. We continue to advocate for the need for specialized knowledge and training about mental health issues for providers and Bayou Health companies serving people with intellectual disabilities. The Advocacy Center is also concerned about the future of the Coordinated System of Care program.

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 monitor access to waiver services for individuals with disabilities, particularly for individuals in group homes. We remain concerned that plans to change the prioritization process for waiver slots will exclude people in group homes from the program because they do not seem to be a high priority and funds will always be limited.

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 is continuing to represent individual students with disabilities in charter schools to access evaluations and prevent unlawful removals from school. Nothing new 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.

Nothing new to report.

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 continues to be concerned about the lack of real progress to implement Employment First. Staff are monitoring sheltered workshops to ensure they are complying with federal wage and hour laws and advocating for systemic changes to promote integrated employment.

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 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.

Nothing new to report.