October 28, 2014

VIA ELECTRONIC AND FIRST CLASS MAIL
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Re: Louisiana's HCBS Waiver Program

Dear Ms. Mann,

The Southern Poverty Law Center and The Advocacy Center submit this letter to highlight certain implementation problems inherent in Louisiana's Coordinated System of Care for children and youth with severe mental health needs.[1]

Thousands of Louisiana's children are diagnosed with some type of behavioral, emotional, or psychiatric disorder. Tragically, all too many of these children spend their youth isolated from their families and communities as they cycle through institutions or detention centers that fail to provide them with adequate mental health care. In 2012, Louisiana restructured its behavioral health services system and created a new program to address the needs of those children and youth most at risk of out-of-home placement, pursuant to a 1915(c) Home and Community-Based Services ("HCBS") Waiver. The new program, the Coordinated System of Care ("CSoC"), promised to offer wraparound planning and care, as well as specialized intensive and community-based services, designed to help children remain in their homes and communities.

Over two years later, Louisiana's implementation of the program remains deeply flawed. Due to service unavailability and waitlists, children in crisis are often arrested and put in detention or hospitals instead of receiving the home and community-based services and supports they need. This failure to provide mandated and essential services not only puts these children and youth in touch with the criminal justice system, jails and hospitals, but is also contradictory to the overarching purpose of CSoC—to keep youth out of institutions and in the community. These failures place Louisiana's children at serious risk of institutionalization in direct violation of both the federal Medicaid Act and the Americans with Disabilities Act ("ADA").

[1] The Southern Poverty Law Center is non-profit civil rights organization dedicated to fighting hate and bigotry and to seeking justice for the most vulnerable members of our society. The Advocacy Center is the federally designated protection and advocacy system for persons with disabilities throughout the state of Louisiana.

BACKGROUND

In March of 2012, recognizing the importance of serving children in their homes and communities, Louisiana restructured its behavioral health services system and created CSoC under its HCBS Medicaid Waiver. CSoC is available to children and youth up to age 21, who have complex behavioral health needs and who are currently in or are at the greatest risk of out-of-home placement, such as detention, psychiatric hospitals, residential treatment facilities, foster care, or alternative schools. The primary goals of the CSoC program include: (1) Reduction in the number of children in detention and residential settings; (2) Reduction of the State's cost of providing services by leveraging Medicaid and other funding sources; (3) Increased access to a fuller array of home and community-based services that promote hope, recovery, and resilience; (4) Improved quality by establishing and measuring outcomes; and (5) Improving the overall functioning of these children and their caregivers.[2]

CSoC offers enrollees wraparound planning and care, as well as five specialized intensive services, with the goal of enabling these children to remain in or return to their homes and communities. A wraparound facilitator works with the child, the child's family, and the child's service providers to develop an individualized plan of care, as well as a crisis plan for emergency situations. The five specialized services that CSoC enrollees receive in addition to regular State Medicaid plan services are: Parent Support and Training, Youth Support and Training, Independent Living/Skills Building, Short Term Respite, and Crisis Stabilization.

The state agency charged with the administration, implementation, and oversight of the CSoC program is the Office of Behavioral Health ("OBH"), a division within the Louisiana Department of Health and Hospitals. OBH has contracted with Magellan Health Services of Louisiana, the Statewide Management Organization ("SMO"), to run the day-to-day operations of the program.

CSoC currently operates in five regions throughout the State. There are 1,200 slots available throughout these five regions, with the most recent data available showing that 1,093 of these slots are filled.[3] On September 29, 2014, CMS approved Louisiana's amendment to its 1915(c) waiver plan to expand the program statewide, which includes adding four more regions and opening up an additional 1,200 slots for those regions. At full implementation, CSoC will be in effect statewide and serve up to 2,400 children and youth throughout the state.

LACK OF ACCESS TO CSoC SERVICES AND PROGRAM

On paper, CSoC is an exemplary program offering Louisiana families much-needed community supports and services, and many families report positive experiences and successes with certain aspects of the program, particularly the wraparound planning and service coordination. However, more than two and a half years after the creation of the program, huge gaps remain in the provision of CSoC services, preventing eligible children and youth from accessing the full benefits

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[2] *See* Louisiana Coordinated System of Care, Standard Operating Procedures, Issued April 10, 2014, p. 1, available at: http://www.magellanoflouisiana.com/media/791326/csoc_sop_final_042014__2_.pdf.

[3] CSoC Data for Statewide Coordinated Council, October 9, 2014, available at: http://csoc.la.gov/assets/csoc/Documents/SCC/2014Oct/20141009CSoCDataforSCC.pdf.

of the program and putting these children at further risk of out-of-home placement. Of equal concern, Louisiana is expanding the program statewide without ever reaching full implementation in the original regions.

An integral part of the CSoC program is the five specialized services specifically designed to keep children with significant behavioral and mental health needs in their homes and communities.[4] However, as set forth in detail below, problems with the administration and implementation of the CSoC program have prevented children and families from being able to access a number of these critical services, including short-term respite care, crisis stabilization, and parent and youth support and training.

A. Lack of Short-Term Respite Care

According to program definitions, short-term respite care services are "designed to help meet the needs of the caregiver and the child. The respite provider cares for the child or youth in the child's home or a community setting to give the child/youth and/or the caregiver/guardian a break. Children or youth in CSoC can receive up to 300 hours of respite each year. This service helps to reduce stressful situations. Respite may be planned or provided on an emergency basis."[5]

Respite care serves two very important purposes: (1) it offers families regular, periodic relief from care giving, and (2) it is a crucial component of a crisis support system. Research shows that respite care is an important social service often needed by families and children with severe emotional disturbance ("SED").[6] Significantly, studies have shown that the provision of respite care results in fewer incidents of out-of-home placement for children with severe emotional disturbance—one of the stated goals of the CSoC program.[7]

Currently, there are an insufficient number of qualified providers for respite care throughout the State, causing waitlists and creating other barriers to access for families enrolled in CSoC. An April 2014 CSoC Report to the Governance Board noted that "there has been a decrease in . . .

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[4] CMS guidance advises that "[c]hildren with significant emotional, behavioral and mental health needs can successfully live in their own homes and community with the support of the mental health services described in this document," including wraparound service planning, family and youth peer support services, respite care, mobile crisis response, and crisis stabilization. *See* Joint CMCS and SAMHSA Informational Bulletin, "Coverage of Behavioral Health Services for Children, Youth, and Young Adults with Significant Mental Health Conditions," May 7, 2013, p. 1, available at: http://medicaid.gov/Federal-Policy-Guidance/Downloads/CIB-05-07-2013.pdf. "These services enable children with complex mental health needs . . . to live in community settings and participate fully in family and community life." *Id.* at 1.

[5] *See* Louisiana Coordinated System of Care, Standard Operating Procedures, *supra* note 2, at 15.

[6] *See* Stroul, B.A., & Friedman, R.M. (1986), *A system of care for severely emotionally disturbed children and youth.* CASSP Technical Assistance Center, Georgetown University Child Development Center.

[7] *See* Bruns, E. & Burchard J. (2000), *Impact of Respite Care Services for Families with Children Experiencing Emotional and Behavioral Problems*. Children's Services: *Social Policy, Research, and Practice,* 3(1), 39-61. Note that in this study of the effectiveness of respite care for families of children with emotional and behavioral disorders, families who received an average of twenty-three hours per month of preplanned respite care reported fewer out-of-home placements, greater optimism about caring for their child at home, and reduced care-giving stress compared with similar families who were on a waiting list. In addition, the families reported that their children displayed fewer negative behaviors in the community.

Short Term Respite" providers, with there being zero providers for this service in one individual CSoC region and too few providers in the regions where the service is available.[8] And although recognizing this "gap in . . . Short Term Respite Care" in the April Report and "actively developing strategic recruitment plans" for finding providers for this service, there have been no improvements.[9] In fact, the July Report to the Governance Board reported no change in the number of respite providers,[10] and the October Report noted that "the number of Short Term Respite service providers has decreased by two since last quarter."[11]

Families and providers participating in CSoC similarly report that respite care remains either nonexistent, unavailable when needed, or at best, inconsistently delivered. For instance, in the New Orleans region, there are an insufficient number of respite providers causing there to be waitlists for this service. Even families we work with who are able to receive some respite care report that its provision is sporadic, fraught with problems, and often unavailable in a crisis situation.

Without access to respite care, families and social service organizations are forced to rely on the very systems that CSoC is set up to divert kids away from. Juvenile court judges, public defenders, social workers, and other community stakeholders advise that because of the unavailability of respite care, children are being arrested, placed in detention, sent to child welfare, or hospitalized in crisis situations.

One juvenile court judge stated that she has children come before her who were arrested out of their homes when a family member had to contact the police during a mental health crisis because there were no other options available to the family. She also stated that she has had to send children in crisis or who otherwise need respite services or a safe place to stay away from their homes to either detention or the child welfare system because respite services were unavailable to them, despite being enrolled in CSoC. Such experiences demonstrate not only the consequences children and families face when unable to access community services they are entitled to, but also the fact that the program is working in direct contravention to its purpose—to keep children out of institutions.

B. Lack of Crisis Stabilization

Similarly, crisis stabilization is also unavailable to children enrolled in CSoC. Crisis stabilization "provides response to crisis situations for a short period of time. It includes intensive resources for the child or youth and his or her family. With this service, the child or youth is placed out of the home for no more than seven (7) days."[12] The explicit purpose of this service is "to

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[8] Coordinated System of Care, Report to the Governance Board, April 24, 2014, p. 5, available at: http://www.csoc.la.gov/assets/csoc/Documents/GovernanceBoard/2014April/20140221DirectorsReport.pdf.

[9] *Id.*

[10] Coordinated System of Care, Report to the Governance Board, July 24, 2014, p. 5, available at: http://www.csoc.la.gov/assets/csoc/Documents/GovernanceBoard/2014July/2014JulyCSoCGvBdDirectorsReport.pdf.

[11] Coordinated System of Care, Report to the Governance Board, October 22, 2014, p. 5, available at: http://www.csoc.la.gov/assets/csoc/Documents/GovernanceBoard/2014October/2014OctoberCSoCDirectorsReportFinal.pdf.

provide an out-of-home crisis stabilization option for the family *in order to avoid psychiatric inpatient and institutional treatment of the youth by responding to potential crisis situations*."[13]

At this time, there are no providers of crisis stabilization in Louisiana, meaning that this service is completely unavailable throughout the entire State. Again, CSoC, Magellan, and OBH have all acknowledged this gap, unequivocally stating just days ago in the October Report to the CSoC Governance Board that "there are no Crisis Stabilization providers in the implemented regions."[14] And although they have known this problem since as early as April 2014,[15] no progress has been made in ameliorating this gap and children remain unable to access this important service.

Discussions with families reveal that many program enrollees have never even heard of this service they are purportedly entitled to receive under CSoC. Crisis plans for children in CSoC further show the unavailability of crisis stabilization and the ramifications the lack of this service may have on a family. Without mentioning crisis stabilization or even respite services, these crisis plans instruct parents to call the police or to take their child to a hospital in the event of a crisis—both of which directly place children in the systems crisis stabilization is designed to help them avoid. As such, the unavailability of this important intervention works directly against the purpose of CSoC and can have profound consequences for Louisiana children.

C. Lack of Parent and Youth Support and Training Services

In addition to respite and crisis stabilization services, CSoC enrollees are unable to access important youth and parent support services. Youth Support and Training is defined as: "Young people who have been involved in behavioral health services or other child-serving systems in the past provide support, mentoring, coaching and skill development to children and youth enrolled in CSoC" at home and in community locations.[16] Parent Support and Training, on the other hand, "connects families with people who are caregivers of children with similar challenges" and provides "information and education to families and help[s] families connect with other community providers."[17] The statewide Family Support Organization ("FSO") is responsible for providing both of these services.

The July Report to the CSoC Governance Board reported that the Family Support Organization "currently has approximately 90 youth awaiting assignment for service. The FSO continues to take measures to address the waitlist."[18] Families, community organizations, judges,

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[12] *See* Louisiana Coordinated System of Care, Standard Operating Procedures, *supra* note 2, at 15.

[13] Louisiana Behavioral Health Partnership (LBHP) Service Definitions Manual Version 8, December 2012, p. 13, available at: http://new.dhh.louisiana.gov/assets/docs/BehavioralHealth/LBHP/ServicesManual-Current.pdf (emphasis added).

[14] Report to the Governance Board, October 22, 2014, *supra* note 11, at 5.

[15] Report to the Governance Board, April 24, 2014, *supra* note 8, at 5.

[16] *See* Louisiana Coordinated System of Care, Standard Operating Procedures, *supra* note 2, at 15.

[17] *Id.*

[18] Report to the Governance Board, July 24, 2014, *supra* note 10, at 2.

and probation officers likewise report waitlists for youth mentoring services for children enrolled in CSoC.

These parent and youth peer supports play an essential role in helping to build the skills and resiliency of caregivers and children and to strengthen the capacity of families to care for children at home. Together, they make up a critical component of the service array intended to help children remain in the community and avoid out-of-home placement. However, as with the crisis services discussed above, a lack of qualified providers for these services has made them unavailable to families and children who have the greatest need for them.

FAILURE TO PROVIDE SERVICES IS A VIOLATION OF FEDERAL LAW

In addition to undermining the explicit goals of the program, by failing to provide these HCBS services and thus placing the children and youth enrolled in the program at serious risk of out-of-home placement, Louisiana is in direct violation of both the Medicaid Act and the Americans with Disabilities Act ("ADA").

Under federal law, any state that participates in the Medicaid program and receives federal matching funds for its Medicaid expenditures must comply with the provisions of the Medicaid Act and the regulations governing the program. *See* 42 U.S.C. § 1396, *et seq.* Furthermore, when a state chooses to provide an optional or additional service, including by opting into a waiver program, "that service becomes part of the state Medicaid plan and is subject to the requirements of federal law." *Susan J. v. Riley*, 254 F.R.D. 439, 451-52 (M.D. Ala. 2008). Therefore, "[o]nce a state opts to implement a waiver program and sets out eligibility requirements for that program, eligible individuals are entitled to those services and to the associated protections of the Medicaid Act." *Boulet v. Cellucci*, 107 F. Supp. 2d 61, 73 (D. Mass. 2000). In other words, once CMS approves a State's HCBS waiver proposal, the State is obligated to provide all the listed services in accordance with Federal Medicaid law, regulations, and guidelines. *Id.*

The "reasonable promptness" provision of the Medicaid Act requires the provision of services with "reasonable promptness to all eligible individuals." *See* 42 U.S.C. § 1396a(a)(8); *see also* 42 CFR § 435.930. Additionally, regulations governing the Medicaid program mandate that once a state elects to provide a service, that service "must be sufficient in amount, duration, and scope to reasonably achieve its purpose." *See* 42 C.F.R. § 440.230(b).

In deciding to implement the Coordinated System of Care pursuant to a HCBS waiver, Louisiana became obligated to provide all the listed CSoC services to eligible individuals in accordance with federal Medicaid law and regulations. And as set forth above, Louisiana has failed to provide certain services to enrollees at all, and failed to provide others with reasonable promptness due to an inadequate number of providers and waiting lists, in direct violation of the Medicaid Act. *See Rosie D. v. Romney*, 410 F.Supp.2d 18, 27-28 (D. Mass. 2006).

In addition to violating the Medicaid Act, Louisiana's failure to provide specialized CSoC services to children and families enrolled in the program also runs afoul of Title II of the ADA, and its integration mandate. *Olmstead v. L.C.,* 527 U.S. 581 (1999). Congress enacted the ADA in 1990 to "provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities." 42 U.S.C. § 12101(b)(1). Title II prohibits discrimination by governmental entities against individuals with disabilities, mandating that "no qualified individual

with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity." 42 U.S.C. § 12132. The ADA's enacting regulations forbid discrimination in the form of unnecessary institutionalization and require that recipients of federal funds provide services and programs to disabled individuals in the "most integrated setting appropriate to the needs" of the individual. *See* 28 C.F.R. § 35.130(d).

The landmark case of *Olmstead v. L.C.* marked the first time the U.S. Supreme Court interpreted the ADA in a way that directly impacted the Medicaid program, finding that unjustified isolation of persons with disabilities is a form of discrimination prohibited by the ADA. 527 U.S. at 597. Accordingly, public entities are required to provide community-based services to persons with disabilities when such services are appropriate. *Id.* at 607. Furthermore, Courts have held that actions that place individuals with disabilities who receive services from the state at serious risk of unjustified institutionalization also violate Title II. *See Fisher v. Oklahoma Health Care Auth.*, 335 F.3d 1175, 1181 (10th Cir. 2003).

By failing to provide community-based crisis and respite services to CSoC enrollees, Louisiana has failed to provide services "in the most integrated setting" in violation of both the ADA and *Olmstead.* This has resulted in the unnecessary hospitalization or detention of a number of youth who could have been served in the community. Furthermore, by failing to provide crisis and respite services, the State has placed all CSoC enrollees—those who have already been determined to be most at risk of out of home placement—at even further risk of unnecessary institutionalization.

RECOMMENDATIONS

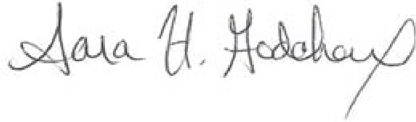
Louisiana's current administration and implementation of the CSoC program is failing those children most at risk. The State has been aware of these problems for some time, but has not taken the appropriate action to remedy this issue and ensure full access to the CSoC program and services. Pursuant to CMS's oversight of Louisiana's HCBS waiver, we request that the agency investigate the cause of the CSoC program's deficiencies, and take all necessary steps to make certain that CSoC enrollees have access to the full array of services and supports to which they are entitled and which they need to remain in the community and avoid institutionalization.

We therefore ask that CMS:

(1) Conduct an investigation into why short term respite, crisis stabilization, and youth and parent support services are unavailable to participants in CSoC;
(2) Take all necessary action to ensure that the CSoC program is providing all the services enrollees in the program are entitled to receive and that enrollees are able to access such services, in compliance with both its waiver application and federal law;
(3) Ensure that the *full array* of CSoC services and supports will be available to children and youth in all regions of the state as the program expands statewide, including short-term respite care, crisis stabilization, and youth and parent support services; and
(4) Ensure that there is an adequate quality assessment process in place to prevent gaps such as these from arising in the future.

We thank you for your prompt attention to this very important matter.

Respectfully,



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