



U.S. Department of Justice

Civil Rights Division

Office of the Assistant Attorney General

Washington, D.C. 20530

DEC 21 2016

Governor John Bel Edwards  
Office of the Governor  
State of Louisiana  
Post Office Box 94004  
Baton Rouge, Louisiana 70804

Re: United States' Investigation, Pursuant to the Americans with Disabilities Act, of Louisiana's Use of Nursing Facilities to Serve People with Mental Health Disabilities

Dear Governor Edwards:

We write to report the Department of Justice's findings from its investigation into Louisiana's delivery of services to people with serious mental illness who reside in nursing facilities across the State. Our investigation assessed the State's compliance with Title II of the Americans with Disabilities Act ("ADA"), 42 U.S.C. § 12101, *et seq.*, which requires that individuals with disabilities receive services in the most integrated setting appropriate to their needs. The Department of Justice is authorized to seek a remedy for violations of Title II of the ADA. 42 U.S.C. §§ 12133-12134; 28 C.F.R. §§ 35.170-174, 190(e). This letter provides notice of the State's failure to comply with the ADA and the minimum steps it needs to take in order to meet its obligations under the law.

We would like to thank the State for the assistance and cooperation extended to the Department of Justice thus far and to acknowledge the courtesy and professionalism of all of the State officials and counsel involved in this matter to date. We appreciate that the State provided us with helpful documents and information in response to our written requests.

**I. SUMMARY OF FINDINGS**

We conclude that Louisiana violates the ADA by unnecessarily relying on nursing facilities to serve people with serious mental illness, rather than providing services in the most

integrated setting appropriate to their needs. The State's systemic failure to provide appropriate community services also places individuals who currently live in the community at serious risk of unnecessary institutionalization in nursing facilities.

Approximately 4,000 people with serious mental illness are currently institutionalized in costly Louisiana nursing facilities where they are isolated and segregated from their families, friends, and communities. On average, these individuals are younger and have fewer physical care needs than the broader nursing facility population. They often spend years in nursing facilities that provide minimal mental health services and apart from paid staff, they rarely interact with people who do not have disabilities. The State has failed to ensure that many nursing facility residents with serious mental illness were offered community-based services as an alternative to nursing facilities. Moreover, through its nursing facility admissions process, the State has approved and facilitated their admission to nursing facilities. These individuals live in more than 250 nursing facilities across Louisiana, but individuals with serious mental illness are frequently admitted to at least eight facilities that are well known placements for people with serious mental illness; and they predominantly house people with serious mental illness.

Most of these individuals could be appropriately served in their own homes and communities if they had the mental and physical healthcare services that Louisiana already provides to thousands of people who have similar needs. Serving individuals in the community is also consistent with Louisiana State law, which requires that individuals with disabilities be served in the least restrictive setting in their own communities. LA. REV. STAT. ANN. § 28:476. Nonetheless, the State continues to fund costly nursing facility placements when people could be served in their communities. The contributing factors to these systemic failures include:

- The State does not identify people with serious mental illness prior to nursing facility admission and divert them into effective, community-based alternatives;
- The State does not identify individuals with serious mental illness currently in nursing facilities, inform them about available options, and provide them with effective transition planning and the community services they need to successfully live in the community; and
- The State does not have a sufficient supply of community-based supports to serve people with serious mental illness who wish to transition from nursing facilities or who are at serious risk of placement in a nursing facility. Furthermore, the State does not make the existing supply of community-based supports adequately available to these individuals.

Louisiana's unnecessary reliance on nursing facilities violates the civil rights of people with serious mental illness. By contrast, community integration will permit the State to support these individuals in settings appropriate to their needs and in a cost-effective manner.

## II. INVESTIGATION

On October 6, 2014, the Department of Justice notified the State of Louisiana that it was opening an ADA investigation into whether the State unnecessarily uses nursing facilities to serve individuals with serious mental illness. Our investigation focused on (1) whether these individuals in Louisiana nursing facilities are appropriate for community-based alternatives; (2) whether they oppose receiving mental and physical health supports in the community; and (3) whether placing them in appropriate, community-based services constitutes a reasonable modification to the State's service system.

During our investigation, we visited numerous nursing facilities across the State, including rural and urban facilities, small and large facilities, and facilities with varying numbers of people with serious mental illness. During our site visits, we and our expert interviewed nursing facility staff members and residents. We also interviewed staff members at community mental health programs, day programs, State psychiatric hospitals,<sup>1</sup> and private hospitals, as well as officials with Louisiana's regional mental health authorities. We met with leadership from the Department of Health in person and via telephone. We also interviewed individuals with serious mental illness who receive mental health services in the community.

In addition to these visits and interviews, we reviewed the documents and information provided by the State, reviewed publically available data and reports, and considered the opinions of a wide range of individuals knowledgeable about the State's mental health system.

## III. LOUISIANA'S PUBLIC MENTAL HEALTH SYSTEM

Louisiana's public mental health system delivers Medicaid- and State-funded services to people with mental illness who meet medical and financial eligibility. The State provides these services through nursing facilities, hospitals, and community-based providers.

### A. Louisiana Uses Nursing Facilities to House People with Serious Mental Illness.

Louisiana has 258 nursing facilities that provide Medicaid-funded services. At any given time, roughly 25,000 Medicaid recipients live in these facilities, which, when compared to other states, house some of the largest numbers of Medicaid recipients on average. Louisiana's percentage of Medicaid certified nursing facilities with 100 beds or more is higher than any other state. And people younger than age 70, many of whom have serious mental illness, make up a sizable and growing percentage of these facilities' residents. In 2013, roughly 33% of the nursing facility population was under age 70, up from 22% in 1999.<sup>2</sup> Moreover, a 2014 AARP

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<sup>1</sup> State psychiatric hospitals will hereinafter be referred to as "State Hospitals."

<sup>2</sup> We note that our investigation did not review the State's compliance with the ADA with respect to people in nursing facilities who have disabilities other than serious mental illness. We

report concluded that about a quarter of all Louisiana nursing facility residents have low-care nursing needs, a higher ratio than all but two other states.<sup>3</sup> Individuals with serious mental illness live in nearly all of Louisiana's 258 nursing facilities, which also house people with age-related disabilities. Many live in facilities that are well known for housing individuals with serious mental illness, including the State facilities at Villa Feliciana and at least seven for-profit nursing facilities around the State.

Despite the passage of two federal laws to prevent this type of segregation,<sup>4</sup> nationally, Louisiana continues to have one of the highest percentages of nursing facility residents with serious mental illness. According to the State, at least 3,856 individuals with serious mental illness—or 14.5% of Louisiana nursing facility residents—lived in Louisiana nursing facilities in October 2014 and roughly the same number continue to live in these facilities as of February 2016.<sup>5</sup> The additional cost to the State of serving individuals with mental illness in nursing facilities instead of the community can be as high as \$7,000 or more per person, per year. And while the State provides community-based services to 20,000 individuals with serious mental illness, it is approving nursing facility admissions for these individuals at a rate of about 1,000 per year. These are individuals without dementia who may also have medical conditions or physical disabilities, such as diabetes, renal disease, and mobility impairments, which are typically accommodated outside of nursing facilities. On average, people with serious mental illness in Louisiana's nursing facilities tend to be younger than the overall nursing facility population and have less intensive support needs. They are institutionalized in nursing facilities

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recognize, however, that some of the systemic failures we identified in this investigation could contribute to the unnecessary institutionalization of people with other types of disabilities. We encourage the State to examine the way these issues impact people with other disabilities and how it can more broadly prevent unnecessary institutionalization.

<sup>3</sup> Susan C. Reinhard, et al., AARP, *Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities and Family Caregivers*, 88 (2014).

<sup>4</sup> See Americans with Disabilities Act of 1990, 42 U.S.C. § 12101, *et seq.*; Nursing Home Reform Act of 1987, 42 U.S.C. § 1396r.

<sup>5</sup> For purposes of this letter, we adopted the methodology used by the State to estimate the number of people with serious mental illness in Louisiana's nursing facilities. As the State did, we excluded individuals with dementia-related diagnoses from the estimate; but we recognize that some individuals with serious mental illness may be misdiagnosed as having dementia. Furthermore, these numbers reflect only Medicaid beneficiaries with serious mental illness. Because of this and other limitations of the information captured by the nursing facility assessments underlying these data, this estimate may be a conservative approximation of the number of people with serious mental illness in Louisiana's nursing facilities.

by reason of their mental illness and may spend many years of their lives there. At least 73% have been institutionalized for more than a year.

Just like persons without disabilities, these individuals have their own unique needs, stories, and goals, but many share a common desire: to live a life of their choosing. One woman with serious mental illness experienced a crisis after the death of a family member, leading to her nursing facility admission. Four years later and still in her fifties, she remained in the nursing facility, despite needing minimal physical and psychiatric care. She longed to go home saying, “I would like to be normal, complete, whole again—like I used to be.” Another woman in her fifties lived with her siblings before coming to the nursing facility, but her siblings decided that they could no longer assist her on their own. In an interview, the woman, who loves to sing, shared her hopes of returning to her hometown and living in an apartment. With appropriate services in place, both of these women could transition from the nursing facility to the community.

Many people with serious mental illness come to Louisiana’s nursing facilities from private psychiatric hospitals, where they are typically admitted for acute care following a mental or physical health crisis. Others come from State Hospitals, or they are admitted to nursing facilities shortly after leaving State Hospitals. One man’s journey into the nursing facility began when he had a mental health crisis a few years ago and repeatedly called 911 about his blood pressure. Instead of connecting him to community treatment services, he was charged with abusing 911, sent to jail, and then admitted to a State Hospital. The State Hospital eventually discharged him to a nursing facility that primarily houses people with serious mental illness. The State approved a six-month stay. Six years later, the man, who is in his sixties, remains in the same nursing facility, even though he wants to return to the community and could do so with proper physical and psychiatric supports. This man’s story is not unique. In addition to the individuals who are discharged from private hospitals, between 2010 and 2014, State Hospitals discharged 153 people with serious mental illness directly into nursing facilities, including some who were discharged as part of its 2011 hospital downsizing effort.

**B. Although Louisiana Redesigned its Mental Health Service System to Provide More Community-Based Services to People with Serious Mental Illness, Services Are Still Inadequate.**

Louisiana’s mental health system has historically relied on high-cost, institutional care to serve its citizens with serious mental illness. This unnecessary reliance has had a detrimental effect on the availability of community-based mental health services, both in terms of the adequacy of funding for services and the numbers of individuals with serious mental illness who have access to care.

The State has, for many years, recognized its reliance on institutional care at the expense of its community-based system. In 2006, a State-commissioned report stated, “By all accounts—

governmental, legislative, judicial, provider, advocacy, consumer, and family member—the availability, accessibility, and quality of treatment and services for Louisianans with mental health conditions are woefully inadequate, and in far too many circumstances, simply nonexistent.”<sup>6</sup> The State again acknowledged in 2011:

Over the last two decades, Louisiana has remained dependent on psychiatric hospital levels of care . . . . While other states were re-organizing their funding approach and moving to a greater proportion of high intensity community based programs, Louisiana continued to have greater fiscal resources directed toward inpatient care.<sup>7</sup>

Similarly, in 2012, the Secretary of the Department of Health and Hospitals<sup>8</sup> stated, “[T]oo many of our resources are invested in large public institutions. This is not the best model of care for our residents or our taxpayers.”<sup>9</sup> The State also identified the solution: “[When] using community-based services like Assertive Community Treatment (ACT) teams, evidence has shown that lengths of stay in inpatient settings will shorten and recidivism rates will improve. Over time, this will decrease demand on more acute inpatient services, which will improve the [S]tate’s capacity to treat the seriously mentally ill.”<sup>10</sup>

Recognizing the urgent need to develop quality, community-based services across the State, the Louisiana Department of Health has worked to redesign its mental health system, to reduce reliance on State Hospitals, and increase access to community-based services. The State consolidated mental health and substance use disorder services in the Office of Behavioral Health and in the ten regional mental health agencies known as local governing entities,<sup>11</sup> closed

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<sup>6</sup> Behavioral Health Policy Collaborative & Technical Assistance Collaborative, *A Roadmap for Change: Bringing the Hope of Recovery to Louisianans with Mental Health Conditions*, at v (June 2006).

<sup>7</sup> Louisiana Office of Behavioral Health, *FY 2012 Combined Behavioral Health Assessment and Plan Block Grant Application*, at 29 (Sept. 1, 2011).

<sup>8</sup> The Louisiana Department of Health was known as the Department of Health and Hospitals until 2016.

<sup>9</sup> Louisiana Department of Health and Hospitals, *DHH Outlines Plan to Establish Sustainable Behavioral Health Care Services for Louisiana Residents* (Aug. 14, 2012), <http://new.dhh.louisiana.gov/index.cfm/newsroom/detail/2571>.

<sup>10</sup> *Id.*

<sup>11</sup> The local governing entities are independent organizations that locally administer the State’s behavioral healthcare system. They offer a core set of services for people with behavioral

one of its three State Hospitals, and downsized the other two. In 2011, the State began investing in community-based services and moving toward a statewide system of community-based care, rather than only having pockets of evidence-based practices available to people with serious mental illness.

Louisiana has also tried to use managed care to reduce its reliance on institutions and improve access to community-based mental health services. In 2012, the State consolidated public behavioral health services under a single managed care entity, Magellan Healthcare, Inc. The State then changed course and in December 2015 transitioned all public behavioral health services to Healthy Louisiana, the State's existing network of Medicaid managed care organizations, with the intention of integrating physical and behavioral health services under the new plan.

Initially, Louisiana intended to include nursing facilities under the umbrella of managed care. As the State explained in a 2013 concept paper, it was influenced by the "consistent suggestion that benefits coordinated through the [long-term service system managed care organization] should be comprehensive and avoid carve-outs, particularly as it related to behavioral health."<sup>12</sup> Advocates for community-based services supported the move, arguing that more nursing facility residents would be transitioned into community-based services by managed care organizations when those services proved to be less expensive than institutionalization. However, the State has not yet solicited proposals to move long-term services and supports into managed care and nursing facilities, therefore, remain exempt.

While the State has taken steps in recent years to develop its community system, its work is far from complete, and the State recognizes that the availability of community-based mental health services is insufficient. It acknowledged last year: "Services to adults are a critical area of need in the [Office of Behavioral Health] system, as prevalence estimates indicate that only a small proportion of the need is being met by existing [Office of Behavioral Health] services."<sup>13</sup> The Substance Abuse and Mental Health Services Administration reports that the percentage of

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health disabilities. Each entity's budget includes State general funds, self-generated funds, and interagency transfers to support programs and services. Beyond the core services provided, entities offer more or fewer services, depending upon their budgets and the needs of their communities.

<sup>12</sup> Louisiana Department of Health and Hospitals, *Transforming Louisiana's Long Term Care Supports and Services System*, at 6 (Aug. 30, 2013).

<sup>13</sup> Louisiana Office of Behavioral Health, *FY 2016 Combined Behavioral Health Assessment and Plan* (Draft), at 55 (July 29, 2015).

Louisianans using mental health services in the community per 1,000 people is less than half the national average.<sup>14</sup>

**C. Louisiana Offers Community-Based Services, Including Assertive Community Treatment, Mobile Crisis Services, Peer Supports, Permanent Supported Housing, and Primary Healthcare.**

Louisiana's existing community-based services are currently inadequate to meet the needs of individuals with mental illness who are in nursing facilities or at risk of entering nursing facilities; however, they include the kinds of appropriate, community-based mental health services necessary for individuals with serious mental illness to live in the community. These services include Assertive Community Treatment, Mobile Crisis services, and peer supports. These are critical, evidence-based practices that can be tailored to the needs of each individual and help them avoid costly, unnecessary, and repeated institutionalization.

**1. Assertive Community Treatment**

Assertive Community Treatment is a community-based service that provides intensive mental health services to individuals with the highest mental health needs and enables service recipients to transition from institutions and live in the community. Assertive Community Treatment teams in Louisiana are designed to address every aspect of an individual's needs, including medication management, therapy, crisis intervention, social support, employment, substance use disorder treatment, and housing. The service is provided by a multidisciplinary team of professionals, including, but not limited to, a licensed mental health professional, housing specialist, employment specialist, substance abuse service provider, nurse, peer support specialist, and psychiatrist. The team is available at all hours, and its members are the primary providers of recovery-oriented services for the individual in the community.

As the State acknowledges in its behavioral health services manual, individuals who have experienced multiple hospitalizations can be successfully served in the community with the assistance of an Assertive Community Treatment team.<sup>15</sup> As of July 2015, there were 14 teams serving only 1,150 people, which is insufficient capacity to serve the needs of individuals with serious mental illness who are currently confined to nursing facilities. Assertive Community Treatment can make all the difference for individuals with a history of institutional placements. One Louisiana woman who had previously been institutionalized in a State Hospital explained the value of her Assertive Community Treatment team in contrast to institutional living:

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<sup>14</sup> Substance Abuse and Mental Health Administration, Center for Mental Health Services, *Louisiana 2013 Uniform Reporting System Mental Health Data Results* at 1.

<sup>15</sup> Louisiana Department of Health and Hospitals, *Louisiana Behavioral Health Partnership (LBHP) Service Definitions Manual, Version 9*, at 118-19 (July 2014).



Who wants to be told what to do so much? Who wants to be away from their mother, father, and children? Who wants to be in a place where there are no hugs, no kisses—a place where you can't enjoy momma's cooking? When you're in an institution, it's like someone took you there and then keeps you in this place where it's aggravating, and it's disgusting. You can't take a bath and a shower when you want to. You can't walk outside when you want to. I need freedom, money, transportation, and I've got a lot of those necessities and more because of [my Assertive Community Treatment provider].

## 2. Community Psychiatric Support and Treatment

Community Psychiatric Support and Treatment and Psychosocial Rehabilitation are two Louisiana Medicaid services that provide individualized mental health supports of varying intensity. Community Psychiatric Support and Treatment is a face-to-face intervention that can take place in community settings and includes supportive counseling, behavioral management and analysis, assistance with identifying crisis triggers, development of crisis management plans, and assistance in restoring the individual's fullest possible integration in the community. Psychosocial Rehabilitation helps people regain independent living and interpersonal skills. While less intensive than Assertive Community Treatment, if implemented in an individualized manner consistent with the person's needs, the combination of Community Psychiatric Support and Treatment and Psychosocial Rehabilitation can be used to provide support similar to the intensive case management services available in other states. In July 2015, 4,845 Louisianans were receiving Community Psychiatric Support and Treatment, and 3,419 people were receiving Psychosocial Rehabilitation.

## 3. Mobile Crisis Services

Louisiana offers limited crisis prevention and intervention services, which include Mobile Crisis and toll-free crisis lines. Mobile Crisis is an evidence-based intervention designed to provide support to individuals in crisis at their homes and in other community locations. Where available, Mobile Crisis teams in Louisiana provide on-site support to help people remain in their homes and avoid inappropriate institutionalization. A 24-hour crisis telephone line is available statewide. A non-crisis line, staffed by peers in recovery, is also available from 5 a.m. until 10 p.m., seven days per week. Some of the local governing entities provide crisis hotlines or contract with third party providers to offer crisis services after hours, on weekends, and on holidays; and some use staff members to substitute when third party providers are temporarily unavailable.

## 4. Permanent Supported Housing

Permanent Supported Housing is an evidence-based practice for successfully supporting individuals with serious mental illness in the community. It includes integrated, community-based housing with tenancy rights, coupled with individualized services and supports that are

necessary to help the individual maintain housing. Permanent Supported Housing promotes mental health recovery by enabling individuals to avoid the inherent stress of housing instability. It helps individuals achieve maximum independence, positive health benefits, and an overall higher quality of life. Permanent Supported Housing is also a cost-effective service that reduces expensive hospitalizations, institutionalization, incarceration, and emergency room visits.

Louisiana's Permanent Supported Housing Program was established in the wake of Hurricanes Katrina and Rita, and is concentrated in the areas most affected by the hurricanes. As a result, there is limited availability of Permanent Supported Housing elsewhere in the State, and there is a long waitlist. The goals of the program are the prevention and reduction of institutionalization and homelessness for people with disabilities, and it supports approximately 2,700 households. Eighty-five percent of current Permanent Supported Housing homes have at least one member with a mental illness, some of whom moved directly into the program from institutions. Some of the local governing entities also operate housing programs through third party contracts that provide various housing alternatives and housing supports.

## 5. Community-Based Primary Healthcare Services

For individuals with serious mental illness who have physical disabilities or chronic health conditions, Louisiana has programs that provide additional supports, such as personal care services, home health, and nursing services, all of which are overseen by the Office of Aging and Adult Services. People with mental illness have higher rates of chronic health conditions than the general population. If these conditions are not properly managed, they often worsen and contribute to the fact that on average, people with serious mental illness die 25 years earlier than those without serious mental illness. Therefore, the need for integrated mental and physical healthcare is critical for people with serious mental illness. Integrating physical and mental healthcare by, for example, embedding primary care providers in mental health centers and coordinating all necessary care through case management has proven successful in reducing hospitalization and adverse outcomes. Accordingly, the State has acknowledged that better coordination of services “increases access to a more complete and effective array of behavioral health services and supports, improves quality of care and outcomes, and reduces repeat emergency room visits, hospitalizations, out-of-home placements, and other institutionalizations.”<sup>16</sup>

The State's most comprehensive package of community-based services for individuals with physical disabilities is the Community Choices Waiver Program, which offers priority access to people in nursing facilities. This program provides services for people over age 65 and

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<sup>16</sup> Louisiana Office of Behavioral Health, *FY 2016 Combined Behavioral Health Assessment and Plan* (Draft), at 8 (July 29, 2015).

people with physical disabilities as a lower cost alternative to nursing facility care. Depending on each recipient's level of need, he or she is provided funding to create an individual, community-based service package. The program contains an array of services to help the individual avoid institutionalization, including support coordination, nursing and skilled therapy, home modifications and assistive technologies, and personal care services. Those found eligible for the program wait an average of 4.35 years for services, and almost 36,000 people are on the program's waitlist. The program is limited to serving 5,303 people at a time; yet at the end of fiscal year 2014, the State had only 4,185 people in it.

In addition to the Community Choices Waiver Program, which is only available to a limited number of people, personal care services and home health services are available to all Medicaid-eligible individuals who need them. Personal care services assist with activities such as grooming, eating, and toileting, as well as laundry, meal preparation, shopping, and medication oversight. Medicaid-eligible individuals can receive up to 32 hours per week of personal care services,<sup>17</sup> while individuals who need more than 32 hours per week may be eligible for the Community Choices Waiver. The State also offers home health services, including diagnosis and treatment of illness or injury by a registered or licensed professional nurse, and assistance with activities of daily living, which are provided by an aide. Individuals in the program may receive up to 50 home health visits per year by a skilled nurse or aide.

#### **IV. FINDINGS**

Nearly 4,000 Louisianans with serious mental illness are confined in costly nursing facilities even though many of them can and want to live in the community and the State system can be reasonably modified to offer placement in the community. We therefore conclude that the State fails to provide services to individuals with serious mental illness in the most integrated settings appropriate to their needs, as required by the ADA.

##### **A. Title II of the ADA Requires States to Serve Individuals with Disabilities in the Most Integrated Setting Appropriate.**

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). Congress found that “historically, society has tended to isolate and segregate individuals with disabilities, and despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem.” 42 U.S.C. § 12101(a)(2). For these reasons, Congress prohibited discrimination against individuals with disabilities by public entities when it provided that “no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of

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<sup>17</sup> Twenty-three thousand Louisianans received personal care services through this program in fiscal year 2014.

the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.” 42 U.S.C. § 12132. Accordingly, the “ADA is intended to insure that qualified individuals receive services in a manner consistent with basic human dignity rather than a manner which shunts them aside, hides, and ignores them.” *Helen L. v. DiDario*, 46 F.3d 325, 335 (3d Cir. 1995).

One form of discrimination prohibited by Title II of the ADA is violation of the “integration mandate.” 28 C.F.R. § 35.130(d); *see also* 42 U.S.C. § 12101(a)(2), (b)(1). That is, under the ADA, public entities are required to “administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” 28 C.F.R. § 35.130(d). An integrated setting is one that “enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible.” 28 C.F.R. Pt. 35, App. B, 690 (2015).

In *Olmstead v. L.C.*, the Supreme Court held that public entities are required to provide community-based services to persons with disabilities when (a) such services are appropriate; (b) the affected persons do not oppose community-based treatment; and (c) community-based services can be reasonably accommodated, taking into account the resources available to the entity and the needs of other persons with disabilities. 527 U.S. 581, 607. In so holding, the Court explained that unnecessary institutional placement “perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life.” *Id.* at 600.

The ADA’s integration mandate applies both to people who are currently institutionalized and to people who are at serious risk of institutionalization. *Steimel v. Wernert*, 823 F.3d 902, 913 (7th Cir. 2016); *Davis v. Shah*, 821 F.3d 231, 263 (2d Cir. 2016); *Pashby v. Delia*, 709 F.3d 307, 321-22 (4th Cir. 2013); *M.R. v. Dreyfus*, 663 F.3d 1100, 1115-18 (9th Cir. 2011), *opinion amended and superseded on denial of reh’g*, 697 F.3d 706 (9th Cir. 2012). As the Tenth Circuit reasoned, the integration mandate “would be meaningless if plaintiffs were required to segregate themselves by entering an institution before they could challenge an allegedly discriminatory law or policy that threatens to force them into segregated isolation.” *Fisher v. Okla. Health Care Auth.*, 335 F.3d 1175, 1181 (10th Cir. 2003); *see also Pitts v. Greenstein*, No. 10-635-JJB-SR, 2011 WL 1897552, \*3 (M.D. La. May 18, 2011) (unpublished) (“A State’s program violates the ADA’s integration mandate if it creates the *risk* of segregation; neither present nor inevitable segregation is required.”). A State’s failure to provide community services may create a risk of institutionalization. *Pashby*, 709 F.3d at 322; *see also Peter B. v. Sanford*, No. 6:10-767-JMC-BHH, 2010 WL 5912259, at \*6 (D.S.C. Nov. 24, 2010) (unpublished) (“[A] State’s failure to provide services to a qualified person in a community-based setting as opposed to a nursing home or institution presents a violation of Title II of the ADA”).

## **B. Nursing Facilities Are Segregated, Institutional Settings.**

It is well established that nursing facilities are segregated settings. *Day v. District of Columbia*, 894 F. Supp. 2d 1, 22-23 (D.D.C. 2012); *Rolland v. Cellucci*, 52 F. Supp. 2d 231, 237 (D. Mass. 1999). “The ADA was passed, in part, to combat discrimination against individuals with disabilities, including discrimination in the form of unnecessary segregation of those with disabilities in nursing homes and other institutions.” *Joseph S. v. Hogan*, 561 F. Supp. 2d 280, 285 (E.D.N.Y. 2008) (denying motion to dismiss in case involving plaintiffs with mental illness who were institutionalized in nursing facilities); *accord Day*, 894 F. Supp. 2d at 22-23; *Conn. Office of Prot. & Advocacy for Persons with Disabilities v. State of Conn.*, 706 F. Supp. 2d 266, 276-77 (D. Conn. 2010); *Peter B.*, 2010 WL 5912259, at \*6.

Nursing facilities in Louisiana are typically institutional in nature, as evidenced by the physical environment, the lack of privacy and autonomy, and the lack of integrated, adult activities for the residents. Louisiana’s nursing facilities congregate an average of 130 people with disabilities in a setting where they receive all of their services on-site in a way that forecloses the opportunity to interact with people who do not have disabilities or are not paid staff. Most facilities have long hallways and locked exits, and some also have locked gates around the exterior of the building. Paging systems, loud televisions in the common areas, and the sounds of other residents create a steady stream of audible interruption at most facilities. When asked about life in the nursing facility, a male resident in his thirties who loves music and has serious mental illness said he sleeps most of the day, explaining, “I don’t want to see what environment I’m in. It’s depressing.”

Louisiana nursing facilities, as is common elsewhere, afford almost no privacy to residents, other than providing minimal storage spaces like a small closet in their bedrooms. Furthermore, most nursing facilities use security cameras to monitor residents’ movements through the facility. While the cameras do not monitor the relatively small bedrooms, even in there, residents still have little privacy, because staff members often come in and out of rooms after a perfunctory knock on the door. Privacy in the bedroom is also drastically diminished by the fact that residents usually share the space with as many as three other roommates. At one facility, which had numerous available rooms and was only 60% full on average, residents were crowded into rooms with as many as three assigned roommates.

Many aspects of nursing facility life are characterized by segregation from the broader community and a lack of autonomy. For example, residents have no access to a kitchen where they can prepare their own food, and they are rarely permitted to do their own laundry. Residents must also submit to regimented mealtimes, and they are rarely allowed to administer their own medications. Almost all residents see on-site doctors and psychiatrists. Some nursing facilities effectively prevent residents from moving about at will by locking exits after certain hours, requiring visitors and residents to sign in and out, prohibiting residents from leaving the facility unaccompanied, and using alarmed doors locked with key codes, even when these types of restrictions are not necessary. Nursing facilities also maintain control over the residents’ money for their personal needs, which is usually less than \$40 of their state and federal benefits;

and if residents want access to it, they must go to a staff member to get it. As one female resident explained, “When you’re at a place like this, you have to fall in line. You do what they tell you to do . . . They say ‘jump,’ you jump.” In describing the nursing facility, one man said “it feels like you’re doing prison time,” and a female resident similarly said she feels “like a prisoner.”

The activities we observed in Louisiana’s nursing facilities were limited, repetitive, and conducted on nursing facility property, rather than in the community. Weekly events include activities like bingo, arts and crafts, and singing karaoke. For example, a 60-year-old man said his nursing facility hosts “auctions” with play money in which the residents can bid for used clothing. With the lack of meaningful engagement, some residents said they were often bored, and they reported spending their days passing the time by watching television, sleeping, or smoking.

Some nursing facilities take residents on organized trips to nearby shopping centers or restaurants; but such outings are limited, rigidly scheduled, and contribute little to community integration. Residents often travel as a group in the facility’s bus or van, and the number of individuals attending the outings may be limited to however many people can fit in the vehicle. A nurse at one facility explained that when residents go on outings, all staff members wear t-shirts bearing the name of the nursing facility so that people in the community will know where the group is from.

Although nursing facilities across Louisiana demonstrate these institutional, segregated qualities, our investigation found that these qualities were particularly acute in at least eight nursing facilities serving large populations of people with serious mental illness. These facilities are well-known in local communities as placements for people with serious mental illness and particularly stigmatizing for the people living at the facilities. As a staff member at one of these facilities explained, “A lot of people in the community don’t think we’re a nursing facility. . . . People think we’re a psychiatric facility.” The State appears to view these facilities similarly: Approximately 65% of people discharged from State psychiatric hospitals into nursing facilities went to these particular facilities. Some of these facilities advertise locked “behavior units,” which isolate individuals with serious mental illness in one part of the building. One nursing facility openly states on its website that the only substantive admission criteria for its “behavior unit” is that residents must be 40 years or older; able to pay with Medicaid, Medicare, or privately; and have a “[p]sychiatric diagnosis[,] with or without medical diagnosis.”

Given the foregoing, we conclude that Louisiana nursing facilities are institutional settings that segregate individuals with serious mental illness away from their homes and communities.

**C. Nursing Facility Residents with Serious Mental Illness Are Appropriate for Community Placement and Do Not Oppose it.**

Our investigation revealed that a significant number of nursing facility residents with serious mental illness throughout Louisiana are appropriate for community placement and want to live in the community. After interviewing nursing facility residents across the State and reviewing their medical records, our expert concluded that many Louisianans with serious mental illness who are in nursing facilities could be served in the community with the help of the physical and mental health services and supports that already exist in Louisiana's service system. For example, a man in his thirties who had previously worked and lived independently now spends his days alone in his room listening to the radio. He wants to go home, and according to our expert, he could be served in the community with integrated physical and mental healthcare, including a low level of direct support. A woman in her fifties came to a nursing facility in 2012 after she was hospitalized for one month. She described herself as desperate to return home so that she can work, take part in meaningful recreational activities, and spend time with people her age. In fact, her goals are realistic. Our expert found that with appropriate community-based services, including Permanent Supported Housing, she could live in the community.

There are individuals who live in the community and receive appropriate care, and they have the same mental health disabilities and needs as those in the nursing facilities. One such man who is being served by an Assertive Community Treatment team said that, prior to receiving community services, he was hospitalized and jailed. However, with the assistance of his Assertive Community Treatment team, he now lives in his own apartment that he "loves." Various team members support him in the community with services like therapy and medication management and help him with basic needs like shopping and laundry. Another man currently served by an Assertive Community Treatment team previously experienced severe depression, homelessness, and incarceration. He attempted suicide and became estranged from his daughter. But with the help of his team, he now has a part-time job and rents an apartment. He is also in daily communication with his daughter, who now calls him "Dad," rather than using his first name.

While many nursing facility residents with serious mental illness have low-care physical needs, our expert also concluded that those nursing facility residents with serious mental illness who do have chronic health concerns may also be served in the community with the appropriate and properly coordinated mental and physical health services. For example, we met with a nursing facility resident who had a history of mental illness in addition to obesity and a leg amputation. Our expert found that he could transition to his own home with a combination of basic mental and physical health services, including personal care services, medication management, and dietary support.

In our investigation, we encountered the common misconception that individuals with serious mental illness are particularly inappropriate for community-based treatment if they have chronic illnesses and physical disabilities. However, that perception is undermined by Louisiana's own success with serving, in the community, nursing facility-eligible individuals with physical disabilities. There were 4,185 people with chronic health needs and physical

disabilities on the Community Choices Waiver at the end of 2014 and about 23,000 individuals receive Medicaid personal care services. Louisiana also had relative success with its Money Follows the Person program, which provides access to enhanced federal funding to transition individuals from nursing facilities to the community. The State used the program to transition 910 nursing facility residents with physical disabilities—but not primarily mental illness—into the community over a five-year period.

The misperception that people with serious mental illness are inappropriate for home- and community-based treatment is especially prevalent among nursing facility staff members, who operate from a nearly uniform assumption that institutionalization is the best option for residents with serious mental illness. Furthermore, staff members often have little familiarity with community-based services that are available for Louisianans with serious mental illness. For example, staff members at one facility said that when residents request a discharge and need community-based mental health services, the facility summons a psychiatrist to persuade the person to reconsider, because staff members do not believe such services are available. The administrator at a different nursing facility said, “We don’t know what a lot of the alternatives are to our facilities because that’s not what we do—the people that we take care of usually can’t stay in their homes or be in the community.” The director of social services at another facility said that when residents want to return to the community, she does not help them if she believes they will need assistance with activities of daily living or medication administration. In fact, however, the very obstacles identified by these staff members can often be overcome with the services and supports Louisiana can provide in the community.

In addition to being appropriate for the community, most of the residents we spoke with expressed their desire to return home to their communities, while others were open to exploring the idea of transitioning to the community if appropriate services were available. For example, a nursing facility resident in his sixties said he wants to leave so intensely that it makes him want to cry. A nursing facility resident in his forties said he wants to work and that “it would mean everything to me to be able to leave and have my own place.” And another nursing facility resident in his forties said he wants to live independently and explained, “I would try to find an apartment to stay in if I could. I’d like to move somewhere so I can take care of my own self.” He also noted that although he sometimes experiences symptoms of a mental illness, “I’m a human too.”

As a consequence of the foregoing, people who could and want to be served in community settings—if they had access to appropriate supports in the community—are instead languishing in institutions that do little to help them return to community life.

**D. Lack of Sufficient Capacity in Existing Community-Based Services and Supports Leads to Needless Nursing Facility Admissions.**



Community-based services, including Assertive Community Treatment, Community Psychiatric Support and Treatment, Permanent Supported Housing, peer support, supported employment, and community crisis services, are essential services for people with serious mental illness in the community. While Louisiana has recognized the critical importance of evidence-based mental health services and included them in its service array, it has fallen short in developing sufficient capacity to meet the needs of individuals with serious mental illness in nursing facilities or who are at serious risk of entering nursing facilities.

One particularly important area where the State has fallen short on service capacity is with its Permanent Supported Housing program. The State acknowledges that the program is a “critical component” of community integration for people with serious mental illness and is making some efforts to expand the program so that it provides housing statewide;<sup>18</sup> however, its capacity is woefully inadequate. Due to the program’s lengthy waitlist and application process, demand outstrips supply and individuals needlessly wait in nursing facilities for Permanent Supported Housing. At least 3,400 people throughout the State need Permanent Supported Housing, and according to the State, because these individuals do not have it, they are institutionalized, living in transitional housing, or homeless. The State recognized a “great need” to expand the Permanent Supported Housing program, particularly in the northern areas of Louisiana,<sup>19</sup> and our investigation confirmed this to be the case. For example, one nursing facility administrator explained that a resident wanted to stay close to his elderly parents, but Permanent Supported Housing was not an option in the area where his parents lived, so he remained in the nursing facility, rather than returning to the community. Similarly, a hospital staff member in northwest Louisiana reported that, because there is neither housing nor support services available in her area, she has sent people to nursing facilities with the State’s assistance. As one of the nursing facility administrators explained, “Some residents could make it in the community and take care of themselves, but you still have to have somewhere for them to go.”

The State has also fallen short in developing other critical evidence-based practices like supported employment, Mobile Crisis services, and Assertive Community Treatment. While the State recognizes the importance of supported employment services to promote recovery of individuals with serious mental illness, it has done little to implement a coordinated statewide program of evidence-based supported employment. Only 10% of adult mental health service recipients in the State (including those with and without serious mental illness) are employed in competitive, full-time jobs.

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<sup>18</sup> Louisiana Office of Behavioral Health, *FY 2014 Combined Behavioral Health Assessment and Plan Block Grant Application*, at 9 (Sep. 1, 2013).

<sup>19</sup> *Id.* at 58, 108.

The lack of crisis services is also a particular problem. The State has rightly acknowledged that “[i]ncreasing alternatives by creating a crisis response network may . . . prevent the unnecessary or inappropriate long-term institutionalization of persons . . . [with] serious mental illness.”<sup>20</sup> The State lacks both availability and consistency in the practice and delivery of crisis services, as evidenced by the fact that only 21 out of 64 parishes offer Mobile Crisis for adults. Providers across the State told us that, when people with serious mental illness are in crisis, they are frequently taken to jails. Assertive Community Treatment is also an essential service that is both understaffed and underfunded. Multiple community providers told us about the need for and lack of Assertive Community Treatment resources in their community. Critically for this population, Louisiana currently lacks an effective system of coordinated and integrated physical and mental healthcare necessary to provide for individuals with serious mental illness who may need more oversight of their medical, mental health, dietary, and rehabilitative services. The fragmentation of care across different providers and services leads to poor outcomes for individuals with serious mental illness, including institutionalization and premature death.

These gaps in mental health services place individuals with serious mental illness at serious risk of admission to nursing facilities and prevent their successful transition to the community. As one nursing facility staff member explained to us, residents are eager to return home, and “[i]f [Louisiana] had good home- and community-based services, it could work, but it’s not there.” Staff members at another nursing facility described a middle-aged resident who called two days after his discharge and asked that someone come get him because the State did not provide the necessary services to assist him with medication management or meal preparation. After being discharged without the necessary psychiatric and personal care supports in place, the man was eventually admitted to a private psychiatric hospital after a suicide attempt. The hospital then discharged him back into the same nursing facility.

The lack of community-based services has similarly delayed transitions from the State Hospital. One State Hospital staff member reported that the biggest obstacle to transition is a lack of resources to match the needs of the person. She nevertheless recalled a former hospital resident who had high needs but who is now living in the community, socially engaged, and thriving after receiving the proper supports. She concluded, “I wish [Louisiana] had more community services available so [we] could do more discharges like that.”

**E. Louisiana Does Not Divert Individuals with Serious Mental Illness from Unnecessary Nursing Facility Placement.**

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<sup>20</sup> Louisiana Department of Health and Hospitals, *A Roadmap for Change: Bringing the Hope of Recovery to Louisianans with Mental Health Conditions*, at 46 (June 2006).

Inadequate capacity in existing services is the primary reason why individuals with serious mental illness are unnecessarily institutionalized in nursing facilities; however, the problem is exacerbated by the State's failure to identify individuals with serious mental illness who are referred for nursing facility admission and promptly connect them with community-based physical and mental health services. Many individuals with serious mental illness are transferred to nursing facilities directly from private psychiatric hospitals or State Hospitals following a physical or mental health crisis, yet most could receive the kinds of community-based services that Louisiana knows how to provide, if these services were made available.

One of the most important tools to divert people from nursing facilities is the Pre-admission Screening and Resident Review process, known as PASRR. Congress enacted PASRR as part of the Nursing Home Reform Act of 1987, which "was passed specifically to end the practice of inappropriately institutionalizing individuals with mental illness . . . in nursing homes." *Joseph S. v. Hogan*, 561 F. Supp. 2d 280, 285 (E.D.N.Y. 2008). An effective PASRR process identifies individuals with mental illness, intellectual and developmental disabilities, or related conditions and determines how those individuals' needs can be met in the community.<sup>21</sup> See 42 U.S.C. § 1396r(e)(7)(A)(i),(G); 42 C.F.R. §§ 483.128(a); 483.130(l); 483.132(a)(1),(2); 483.134(b)(3),(5),(6); *Preadmission Screening and Resident Review (PASRR)*, <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Institutional-Care/Preadmission-Screening-and-Resident-Review-PASRR.html>.

Under PASRR, states must follow "stringent procedures" in implementing a two-level screening and evaluation process prior to nursing facility admission, with limited exceptions.<sup>22</sup> *Hogan*, 561 F. Supp. at 285; see also 42 U.S.C. § 1396r(e)(7)(A)(i); 42 C.F.R. §§ 483.104, 483.106, 483.128(a), 483.132(a). The PASRR Level I screen should identify any individual who might have a mental illness or an intellectual disability. 42 C.F.R. § 483.128(a). If the PASRR Level I screen indicates that the individual may have a mental illness, an intellectual disability, or a related condition, the State must apply the more rigorous PASRR Level II evaluation, which is designed to determine (a) whether an individual's needs can be met in the community; or (b) whether, and what, specialized services can be provided in a nursing facility that will meet

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<sup>21</sup> Consistent with federal law, 42 C.F.R. § 483.102, *et seq.*, Louisiana regulations also mandate that a PASRR screening and evaluation must "be performed for all individuals seeking admission to a Medicaid-certified nursing facility, regardless of the source of payment for the nursing facility services or the individual's known diagnoses." La. Admin. Code tit. 50, pt. II, § 501, 50 LA ADC Pt II, § 501.

<sup>22</sup> PASRR regulations permit the State to exempt individuals from the evaluation process when they are discharged from a hospital and are expected to be in a nursing facility for less than 30 days. 42 C.F.R. §§ 483.106(b)(2). In order to prevent inappropriate transfers from psychiatric hospitals, however, states can elect to disregard the hospital exemption and require full PASRR evaluations for all individuals with serious mental illness.

the individual's needs. 42 C.F.R. §§ 483.132(a)(1),(2); 483.134(b)(5). The PASRR Level II evaluation requires a "functional assessment of the individual's ability to engage in activities of daily living and the level of support that would be needed to assist the individual to perform these activities while living in the community." 42 C.F.R. § 483.134(b)(5). The assessment "must determine whether this level of support can be provided to the individual in an alternative community setting or whether the level of support needed is such that [nursing facility] placement is required." *Id.* Essentially, every PASRR Level II evaluation should provide a plan for receiving services in the home and community, regardless of the perceived availability of services.<sup>23</sup>

In the 2015 PASRR National Report, the federally-funded PASRR Technical Assistance Center stated, "PASRR requires that individuals with [serious mental illness] . . . not be admitted to Medicaid-certified nursing facilities . . . until a full assessment is made, community alternatives are identified, and person-centered services are recommended to meet the individual's medical and PASRR disability-related needs." The report describes the failure to use PASRR to connect individuals to community alternatives as "both a civil rights violation and a personal tragedy" for those who are inappropriately placed in institutional settings. The report concludes, "PASRR is not merely an administrative step in the nursing home admission process—a series of boxes to be checked. On the contrary, PASRR affects lives."

Unfortunately, Louisiana's PASRR program does little to prevent the unnecessary institutionalization of individuals with serious mental illness in nursing facilities; rather, it helps facilitate their admission. In 2007, after finding a nursing facility approval rate of 85% in a five-state survey, the United States Department of Health and Human Services' Office of Inspector General reported that "the PASRR process does not appear to be used as a tool to systematically consider alternative placements to nursing facilities."<sup>24</sup> At an 86% approval rate, Louisiana is unfortunately no exception. According to the State, between fiscal years 2010 and 2014, it conducted 6,142 Level II PASRR determinations for people who were suspected of having mental illness. Of those individuals, the Office of Behavioral Health referred 4,595 (75%) for indefinite nursing facility placement and an additional 697 (11%) for temporary nursing facility placement. Only 14% were referred to community-based services.

PASRR Level II evaluations must involve the participation of the individual and be comprehensive, individualized, and conducted by independent assessors. 42 U.S.C. § (e)(7)(F);

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<sup>23</sup> In furtherance of their obligations under the ADA, states should use these plans to identify gaps in services on a case-by-case basis and by collating the data and using it to drive the development of evidence-based, cost-effective community supports and services.

<sup>24</sup> Department of Health and Human Services, Office of Inspector General, Department of Health and Human Services, *Preadmission Screening and Resident Review for Younger Nursing Facility Residents with Serious Mental Illness*, 28 (January 2007).

42 C.F.R. §§ 483.128, 483.130, 483.134. Louisiana's PASRR Level II evaluations, and thus determinations, fall far short of these requirements, and these shortcomings contribute directly to the State's failure to divert individuals with serious mental illness from unnecessary nursing facility placements.

Many of the 6,142 PASRR determinations between 2010 and 2014 were based almost exclusively on paperwork from hospitals seeking to discharge patients to other locations.<sup>25</sup> A mere 25 individuals out of 6,142 received an in-person evaluation by an entity other than the one referring the person to the nursing facility.<sup>26</sup> Although Level II evaluations and determinations should involve rigorous consideration of whether an individual's needs can be met in the community, in Louisiana this rarely appears to be the case.

The regulations require comprehensive assessment of the individual's history and current supports, as well as functional assessments of the full range of activities of daily living, including grooming, self-care, managing finances, nutrition, medication management, and the supports needed to provide the necessary level of care in the community. 42 C.F.R. § 483.134(b). Louisiana's PASRR Level II determinations show that the State frequently admits individuals with serious mental illness to nursing facilities or extends their stay without meaningful analysis of whether and how individuals' needs can be met in the community.

The local governing entities, the mental health authorities who could provide or arrange for community services, appear to have no involvement in the screening or diversion process for individuals with mental health needs. Compounding this problem, several nursing facility administrators readily concede that much of their business comes from individuals with serious mental illness who are given no other place to go by the State. Moreover, these facilities admit individuals with temporary Medicaid and/or PASRR nursing facility approvals and then

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<sup>25</sup> The State may contract with qualified staff at referring entities to conduct PASRR evaluations as long as the entity has no direct or indirect relationship with a nursing facility and has negotiated a payment rate for the evaluation. PASRR Technical Assistance Center, *Can Hospitals Perform Level II Evaluations?*, (June 11, 2014), <http://www.pasrassist.org/resources/level-ii-personnel/can-hospitals-perform-level-ii-evaluations>.

<sup>26</sup> As of February 2016, if the Office of Behavioral Health determines that a further face-to-face PASRR Level II evaluation is warranted, hospitals are required to refer the individual to his or her managed care organization. Department of Health and Hospitals, *Bayou Health Informational Bulletin 16-4*, 1 (Feb. 24, 2016). Louisiana's nursing facilities are not under managed care; therefore, there is little incentive for its managed care organizations to avoid nursing facility placements and create meaningful opportunities for community-based services.

repeatedly file extension paperwork with the State<sup>27</sup> until a temporary approval becomes a long-term placement, which effectively precludes a meaningful opportunity to access community services.<sup>28</sup>

Louisiana has failed to build an effective diversion system, resulting in the unnecessary institutionalization of individuals with serious mental illness. This is likely reflected not only in the nursing facility population, but also in the State's homeless population (1,168 homeless individuals with serious mental illness) and unnecessary incarceration. The State must properly identify qualified people with serious mental illness who are not receiving appropriate services in the community and connect them with services in the most integrated settings appropriate to their needs. It must also identify people with serious mental illness who are referred for admission to nursing facilities; promptly arrange for appropriate community-based services; and for those few who must be admitted to nursing facilities, immediately begin planning to discharge those individuals into appropriate services in the community.

#### **F. Louisiana Fails to Transition Nursing Facility Residents with Serious Mental Illness into the Community.**

Louisiana lacks an effective system to identify individuals with serious mental illness in nursing facilities who could be served in the community with appropriate supports. It does not regularly educate and inform individuals about their community-based options, and it does not plan for and implement transitions for individuals admitted to nursing facilities. As a result, once individuals with serious mental illness are admitted into nursing facilities, it is difficult for them to return to their communities, particularly after they have lost their housing and natural supports. As one community provider said, "Once someone goes to a nursing facility, we typically never see them again."

After facilitating admission to a nursing facility, neither the Office of Behavioral Health nor the local governing entities have much ongoing contact or involvement with individuals with serious mental illness who are in nursing facilities. More particularly, the State has minimal involvement in planning for these individuals' transition to the community. To the extent that transition planning does occur, it falls on the nursing facilities, which have neither the expertise

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<sup>27</sup> To the extent that Louisiana is making PASRR Level II determinations based upon evaluations and medical records created by the nursing facility or its contractor, this runs afoul of PASRR, which prohibits a "nursing facility or an entity that has a direct or indirect relationship with a nursing facility" from completing Level II evaluations. *See* 42 C.F.R. § 483.106(e)(3).

<sup>28</sup> PASRR separately requires that, if an individual must be admitted to the nursing facility, the State must ensure that the person receives any needed specialized services for mental health, in order to ameliorate the symptoms that "necessitated institutionalization" in the first place. 42 C.F.R. § 483.120. But our investigation revealed that when Louisiana refers individuals with serious mental illness to nursing facilities, many receive minimal specialized mental health services and little assistance to return to the community promptly.

in navigating the community mental health system nor the incentive to facilitate transitions to the community.

Failure to ensure that individuals who do transition out of nursing facilities have the necessary community-based services can result in significant harm and preventable hospital and nursing facility admissions. For example, a woman in her early fifties who lived in a nursing facility was eventually identified for transition back to the community but was discharged with only a segregated day program to meet her psychiatric needs. Shortly thereafter, the nursing facility received a call from a private psychiatric hospital requesting her readmission because she had been hospitalized following a mental health crisis.

The State's failure to take responsibility for transitioning individuals with serious mental illness to the community, and the unsuccessful transitions that result, often lead nursing facility staff members to conclude that services do not exist in the community to support this population. Consequently, nursing facility staff members sometimes discourage people from leaving or do not respond to their requests for assistance to leave. One man in his early fifties would very much like to move out after ten years in the nursing facility, but his plan of care actually prohibits discharge discussions during quarterly reviews. A woman in her fifties said she prefers to live in an efficiency apartment where she would not need a wheelchair to get around, but she knows that no one is actively looking for a place for her. Her plan of care stated, "[The resident] desires to return to the community, but appropriate placement must be found when she is medically stable enough to care for herself." Her discharge plan, however, said, "[The] resident has no other place to go at this time." Our expert found that, like many other nursing facility residents we interviewed, both of these people could be served in the community with the appropriate services and supports.

The State is also not effectively using the PASRR Level II process to identify people who were admitted to the nursing facility but have subsequently become good candidates for transition. Upon observing a "significant change in the resident's physical or mental condition," nursing facilities must send a referral to the State for a new independent evaluation and eligibility determination. 42 U.S.C. § 1396r(e)(7)(B)(iii). Therefore, a significant improvement of the original conditions that brought the person to the nursing facility should trigger a new PASRR evaluation. However, even in instances where residents' medical conditions improved, we found that PASRR evaluations were often missing from nursing facility resident records or were not done at all. We also found that people with serious mental illness transfer between nursing facilities when their needs change, yet they nonetheless escape detection by the State's PASRR system.

Although PASRR does not require reevaluation for a transfer between nursing facilities, a transfer based on or required by behavioral changes (either positive or negative) should trigger a PASRR Level II reevaluation and provide an opportunity to consider whether the individual's needs might be better addressed with evidence-based community mental health services. *See* 42

U.S.C. § 1396r(e)(7)(B)(iii); 42 C.F.R. § 483.106(b)(4). The State does not do so, thereby missing another chance to connect individuals with essential community-based services.<sup>29</sup>

The State's efforts to prevent lengthy nursing facility stays and identify individuals appropriate for transition have fallen short. For example, Louisiana offers general webinar and video trainings on the PASRR process and discharge planning for nursing facilities. The State has also begun doing time-limited authorizations of nursing facility placement for individuals with serious mental illness. The lack of sufficient community-based services and the State's failure to facilitate individuals' return to the community ensure that people often remain past the initial authorization period on State-granted extensions.

The State identifies individuals in nursing facilities for transition through its "level of care initiative," but to the degree the initiative is intended to systemically identify people with serious mental illness who are appropriate for the community, it is misguided and results in poorly implemented transitions. The initiative identifies residents for potential discharge if their physical needs do not qualify for nursing facility care. It does not, however, identify all nursing facility residents with serious mental illness who want, and could be served with, appropriate services and supports in the community. Whether individuals with serious mental illness are eligible for institutional care has little bearing on whether they can be served in an integrated setting. And many individuals with serious mental illness who live in Louisiana nursing facilities qualify for nursing facility level of care, but can nonetheless be served in the community with appropriate services and supports.

When individuals are identified for discharge, they are often released with woefully insufficient community services and supports. The State's involvement in, and oversight of, the transition process typically consists of sending notices to nursing facilities and to the resident, informing the nursing facility that it must discharge the resident, and stating that it will cut off Medicaid funding for the resident if he or she remains. As of November 2014, the State's level of care initiative identified 624 nursing facility residents with serious mental illness who no longer qualified for a nursing facility. The State cannot account for what happened to many of these individuals following discharge. The State is aware that about ten of these individuals returned to the same nursing facility where they previously lived, and ten others are known to have accessed community-based services of some kind. These data typify the State's hands-off approach to transition planning, implementation, and oversight. Without comprehensive discharge plans and transition services, many of the individuals discharged through the level of care initiative are at risk of re-institutionalization.

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<sup>29</sup> The State misses another opportunity to identify individuals for transition by failing to accurately track individuals with PASRR evaluations through the nursing facility assessment data.



One nursing facility administrator expressed his concern that the clock was ticking down for 15 residents who had been identified for discharge as a result of the State's level of care initiative. His staff members were struggling to connect residents with proper services, particularly housing, before the State-imposed deadlines expired. In fact, some nursing facilities report that when they contact the State to ask where residents are supposed to go after discharge, they are told to send them to homeless shelters.

Louisiana also participates in the Money Follows the Person program, which provides access to enhanced federal funding to transition individuals from nursing facilities to the community. However, the program has not significantly benefited people with serious mental illness, because the State has made no particular effort to use this program to transition them from nursing facilities. The Office of Behavioral Health is not a participating agency in the program, and individuals with serious mental illness are not a target population. This program has helped people who have physical disabilities, intellectual disabilities, or traumatic brain injury, and also have co-occurring mental health diagnoses. However, it is not designed to serve individuals whose primary need is for intensive mental health services provided through the Office of Behavioral Health.

Finally, the State also fails to effectively use Section Q of the Minimum Data Set<sup>30</sup> to identify individuals interested in transitioning back to the community. All Medicaid-funded nursing facilities are required to use Section Q to make referrals for community-based living from nursing facilities. Section Q is a survey which, "if followed correctly, gives the resident a direct voice in expressing preference and gives the facility means to assist residents in locating and transitioning to the most integrated setting."<sup>31</sup> Accordingly, when a resident responds to the Section Q survey and indicates that he or she is interested in returning to the community, the nursing facility is required by the State to make a referral to the Local Contact Agency. However, less than 14% of the 137 individuals whom nursing facilities recorded as expressing

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<sup>30</sup> The Minimum Data Set is a comprehensive assessment of all nursing facility residents' functional capabilities and needs. Section Q of the Minimum Data Set requires nursing facilities to ask residents if they wish to speak to someone about returning to the community and thereafter be referred to the State's designated Local Contact Agency. The Minimum Data Set also allows states to introduce optional questions to gather data points not otherwise included in the assessment. Nursing facilities are responsible for administering this assessment on a regular basis. States can examine Minimum Data Set data to identify individuals with particular characteristics that may suggest they are appropriate for and do not oppose community placement, and these include individuals who respond positively to Section Q's inquiry about community living.

<sup>31</sup> United States Department of Health and Human Services' Office for Civil Rights, *Guidance and Resources for Long Term Care Facilities: Using the Minimum Data Set to Facilitate Opportunities to Live in the Most Integrated Setting*, 1 (May 20, 2016).

interest in returning to the community in 2014 were even referred to the Local Contact Agency, and only two were actually discharged with community services. Indeed, of the nursing facilities that identified people who were interested in speaking with someone about community services, more than 80% failed to refer any of those individuals to Local Contact Agencies.<sup>32</sup>

Our investigation further found that the State’s MDS Section Q data significantly underestimates the number of individuals who want to leave nursing facilities. This is likely due to the fact that Louisiana nursing facilities have vastly different methods for recording and using Section Q surveys. For example, some nursing facilities never record “yes” answers, even when there are individuals at such facilities who state that they are eager to return to the community. At one facility, we learned that staff members are actually trained to record an answer of “no” on Section Q, regardless of the resident’s wishes, if the staff member does not believe the resident can leave.

The State does not have an effective system of identification, diversion, or transition of individuals with serious mental illness from nursing facilities to appropriate community-based settings. Instead, it often places individuals with serious mental illness in segregated nursing facilities, solely relies on nursing facilities to discharge residents, and fails to ensure that individuals with serious mental illness transition to the most integrated setting appropriate to their needs.

**G. Louisiana Can Reasonably Modify its Mental Health System to Serve People with Serious Mental Illness in Integrated Settings.**

The Louisiana Office of Behavioral Health has stated: “It is our conviction, that the community where the person chooses to live and work is an appropriate place to provide treatment, supports, and services.”<sup>33</sup> Accordingly, the Office of Behavioral Health’s mission is “to lead the effort to build and provide a comprehensive, integrated, person-centered system of prevention and treatment services that promote recovery and resilience for all citizens of Louisiana.”<sup>34</sup> As the State has acknowledged: “Individuals with serious mental illnesses and addictive disorders often have co-occurring chronic medical problems. Therefore, it is important

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<sup>32</sup> The situation has not substantially improved since 2014. The nursing assessment data reveals that as of February 2016, approximately 240 people expressed interest in learning about community services sometime in the preceding year, but only a quarter were referred to Local Contact Agencies.

<sup>33</sup> Louisiana Department of Health and Hospitals (Division of Planning and Budget), *A Five Year Strategic Plan (FY 2014-2015 through FY 2018-2019)*, 154 (July 1, 2013).

<sup>34</sup> *Id.*

to enhance a collaborative network of primary health care providers within the total system of care.”<sup>35</sup> These goals align with Louisiana State law, which provides that “persons with mental or physical disabilities are entitled to live in the least restrictive environment in their own community and in normal residential surroundings and should not be excluded therefrom because of their disabilities.” LA. REV. STAT. ANN. § 28:476.

Within the State’s mental health service array, Louisiana already provides many of the services and supports that are essential to helping people with serious mental illness live in their homes and communities, including Permanent Supported Housing, Assertive Community Treatment, Community Psychiatric Support and Treatment, Mobile Crisis services, and peer support. While these services are insufficient to meet demand, the State can redirect money it is currently spending on 24-hour nursing facility placements to fund services that help individuals with serious mental illness transition back to or remain in their own homes.

The State may also save money in doing so. For example, State data indicates it results in a reduction in Medicaid costs for people in the program. More generally, when compared to the estimated annual cost of roughly \$22,000 in State funding for a full year of nursing facility services,<sup>36</sup> community services for an individual with serious mental illness can generally be provided for \$15,000 to \$20,000 a year in State costs, even if the person requires the most intensive assistance from an Assertive Community Treatment team, a personal care attendant, and Permanent Supported Housing. This would save the State up to 30% of its nursing facility cost. Moreover, as our expert found, although many Louisianans with serious mental illness would initially need more intensive services upon transition into the community, those needs would likely decrease over time, thus further reducing the costs.

The State’s system for identification, diversion, and transition planning can be strengthened to ensure that people with serious mental illness are placed in appropriate community settings, rather than institutionalized in nursing facilities. Many of the necessary steps forward for the State are already part of the State’s obligations under PASRR, which require the State to identify people with serious mental illness, ensure that accurate evaluations are conducted independently, and connect them to community-based services. 42 U.S.C. § 1396r(e)(7)(B)(i); 42 C.F.R. §§ 483.128(a), (f); 483.130(l); 483.132(a),(b); 483.134(b)(5). Moreover, the State already has mechanisms in place to conduct PASRR evaluations and identify individuals with serious mental illness who should be served in the community. The State can strengthen these mechanisms, for example, by involving the local governing entities in Level II

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<sup>35</sup> Louisiana Office of Behavioral Health, *FY 2012 Combined Behavioral Health Assessment and Plan Block Grant Application*, at 64 (Sept. 1, 2011).

<sup>36</sup> The total Medicaid cost of a full year in a nursing facility is approximately \$59,000 in Louisiana, but the State pays only 38% of that amount—approximately \$22,000—and the federal government pays the remainder.

PASRR evaluations and by providing transition planning for people with serious mental illness, just as the State already does for individuals with intellectual and developmental disabilities. In addition, through its level of care initiative, it has shown itself capable of using available data to identify at least some portion of the nursing facility population that can live in the community.

Given the array of mental health services in Louisiana, the existence of funds that could be directed to community-based settings, and the State's ability to build upon existing processes for diversion and transition, Louisiana can reasonably modify its service system to provide mental health services in the most integrated setting appropriate.

## **V. RECOMMENDED REMEDIAL MEASURES**

The State should promptly implement remedial measures to protect the civil rights of individuals with serious mental illness in, or at serious risk of entering, nursing facilities and to remedy the deficiencies discussed above, taking into account the needs and preferences of each individual with serious mental illness. These remedial measures should include the following:

- The State must improve the capacity of evidence-based community mental health services such as Assertive Community Treatment, Community Psychiatric Support and Treatment, peer support services, supportive employment, Mobile Crisis services, and Permanent Supported Housing. The State should ensure coordination between local government entities and community mental health providers and hospitals, law enforcement, homeless shelters, and jails to avoid unnecessary institutionalization and criminal justice involvement.
- The State must ensure the availability of sufficient home-based medical services and supports, including personal care assistance, home health, and nursing to meet both the needs of individuals with serious mental illness who want to transition to the community from nursing facilities and individuals who are at serious risk of nursing facility admission.
- The State must ensure that necessary physical and mental health services are delivered in an integrated, coordinated fashion.
- The State must develop an effective system of identifying and diverting individuals with serious mental illness from nursing facility placement. To implement an effective process, the State should, at a minimum:
  - Identify people with serious mental illness who are referred for admission to nursing facilities;
  - Ensure that individuals with serious mental illness requesting admission are evaluated by an independent evaluator who is familiar with the available community-based services; and
  - Promptly arrange for necessary behavioral and primary healthcare services in the community where appropriate.

- The State must develop an effective system of identifying and diverting individuals with serious mental illness from nursing facility placement. To implement an effective process, the State should, at a minimum:
  - Identify people with serious mental illness who are referred for admission to nursing facilities;
  - Ensure that individuals with serious mental illness requesting admission are evaluated by an independent evaluator who is familiar with the available community-based services; and
  - Promptly arrange for necessary behavioral and primary healthcare services in the community where appropriate.
- The State must develop a functioning PASRR system that includes comprehensive and meaningful independent assessments and community service planning for all individuals with serious mental illness referred to nursing facilities.
- The State must implement effective, person-centered transition planning for all individuals with serious mental illness institutionalized or at risk of institutionalization in a nursing facility.
- The State must provide quality services in sufficient amount to ensure individuals with serious mental illness receive the services necessary to avoid institutionalization and are integrated in the community.

We are obligated to advise you that if the State declines to enter into negotiations or if our negotiations are unsuccessful, the United States may take appropriate action, including initiating a lawsuit, to ensure the State's compliance with the ADA. However, we would prefer to resolve this matter by continuing to work cooperatively with the State and we are confident that we will be able to do so.

We will contact you soon to discuss the issues referenced in this letter and to set a date and time to meet in person to discuss a remedial framework in which to address any outstanding concerns. Please note that the letter is a public document that will be posted on the Civil Rights Division's website. If you have any questions, please feel free to contact Steven H. Rosenbaum, Chief of the Civil Rights Division's Special Litigation Section, at (202) 616-3244.

Sincerely,



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