Investigation of Missouri's Use of Nursing Facilities and Guardianship for Adults with Mental Health Disabilities

United States Department of Justice
Civil Rights Division

June 18, 2024

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SUMMARY OF FINDINGS

Thousands of Medicaid-eligible adults with mental health disabilities living in Missouri's skilled nursing facilities (often referred to as nursing homes or Level II facilities) are unnecessarily separated from their communities. Around half of them are under 65. Most require little or no assistance with basic physical activities. On average they have been in nursing facilities for at least 3 years. Half of this group is clustered in just 39 of Missouri's 500 nursing facilities. Many of them are under guardianship, with all decisions about every part of their lives made by another person.

These adults are subjected to unnecessary stays in nursing facilities generally because of a series of systemic failures by the State. Specifically, the State fails to provide sufficient community-based services, fails to assertively engage people who have struggled with traditional services, and improperly relies on guardianship for people who have frequent hospitalizations or otherwise are not engaged in treatment. When a guardian is appointed for a person with a mental health disability, the guardian can, and frequently does, place the person in a nursing facility. One provider called guardianship in Missouri a "sentence to be locked in a [nursing facility]."

Carmen[1] is one of the many people we met who experienced guardianship as a pipeline to a nursing facility in Missouri. Carmen spent much of her childhood in and out of hospitals. After she turned 18, a hospital where she had been admitted petitioned for the appointment of a guardian, and the guardian placed her in a nursing facility. Carmen's cousin said they talk in their family about how Carmen slipped through the cracks and did not get the services she needed before or after her placement in a nursing facility. As of February 2024, Carmen had spent over two years in a nursing facility.

Like Carmen, Pamela also cycled in and out of psychiatric hospitals and was placed under guardianship and, ultimately, in a nursing facility. "Pamela has tons of potential—she's capable of much more than she's allowed," said Pamela's mother, who has struggled to get Pamela the mental health services she needs to live in the community. "The system isn't set up to benefit the people they are there to serve." This report highlights many more stories like Carmen's and Pamela's.

Almost uniformly, adults with mental health disabilities in Missouri's nursing facilities do not want to live in these institutions. They dream of lives integrated into the community, consistent with the Americans with Disabilities Act's (ADA) requirements. They want to enjoy simple pleasures of daily living, like going to a fair, spending time with friends and family, having a pet, working, and simply being "independent." Angela, who is in her late 50s and was placed in a nursing facility by her guardian told us: "I have a dream that one day I will be free. Free to live on my own, free to live within my community, free to have overnight visits with my grandchildren, free to not be told who I can associate with, free to not have someone place me in a nursing home and leave me, without any regard to my well-being mentally and physically, most of all just free to live my life."

[1] All the people discussed in this report are identified using random pseudonyms.

We found that almost none of the adults with mental health disabilities living in nursing facilities in Missouri need to be in these institutions, even for short-term stays.[2] Key mental health services—including Assertive Community Treatment, Permanent Supportive Housing, supported employment, peer support, crisis services, and outreach and engagement—could support these adults living in their own homes and communities. Instead of providing sufficient community-based services that the State admits could prevent institutionalization and guardianships, the State promotes and facilitates the use of guardianships and nursing facilities for adults with mental health disabilities. Instead of diverting people with mental health disabilities from unnecessary nursing facility admission or transitioning people from nursing facilities who do not need to be there, people are sent out of sight and out of mind. Instead of focusing resources and attention on serving this group of people in the community, the State relies on nursing facilities as a key piece of the system for serving people with mental health disabilities.

Under the ADA, the State must make reasonable modifications to enable adults with mental health disabilities to live in the most integrated setting appropriate to their needs.

INVESTIGATION

After receiving a complaint, the Department of Justice (DOJ) opened this investigation on November 16, 2022. We examined whether Missouri unnecessarily institutionalizes adults with mental health disabilities[3] in skilled nursing facilities and whether the State's use of guardianship for these adults contributes to the institutionalization. During the investigation, DOJ attorneys, investigators, analysts, and expert consultants:

- Reviewed documents and data, including policies, reports, Medicaid billing information, and individual treatment records of a sample of adults who are living in nursing facilities.

- Interviewed over 30 State officials and dozens of public administrators—the county officials who are often appointed as guardians for adults with mental health disabilities. We also interviewed over 130 directly impacted people and stakeholders including current and former nursing facility residents and their loved ones, people under guardianship, mental health and guardianship advocates, and lawyers. These interviews included conversations at an in-person listening session in Kansas City.

- Visited over 60 providers and facilities, including nursing facilities, community mental health providers, crisis centers, psychiatric hospitals, and housing sites for people with mental health disabilities across Missouri.

[2] As discussed below, adults with mental health disabilities in Missouri tend to be placed in nursing facilities for their mental health symptoms. However, these settings are not intended for and do not offer intensive mental health treatment.

[3] Mental health disabilities refer to diagnosable mental, behavioral, or emotional disorders that cause an impairment that substantially limits one or more major life activities. *See* 42 U.S.C. § 12102.

DOJ appreciates the State's assistance, cooperation, and openness throughout the investigation. We thank the people with mental health disabilities who shared their own stories, and the community stakeholders who provided valuable information.

LEGAL FRAMEWORK

The ADA provides a "clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities."[4] Under Title II of that Act, public entities may not discriminate based on disability.[5] One form of prohibited discrimination is unnecessary segregation.[6] Segregation in an institution is unnecessary when (1) alternative community-based services are appropriate, (2) the affected people do not oppose community-based services, and (3) community-based services can be reasonably accommodated within the State's broader disability service system.[7] Instead of discrimination by segregation, the law requires that public entities "administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities."[8] "The most integrated setting" is one that "enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible[.]"[9]

Congress' decision to prohibit unnecessary segregation arises from its findings that "historically, society has tended to isolate and segregate individuals with disabilities," and that this isolation and segregation continues and persists in "critical areas" like institutionalization.[10] The decision "reflects two evident judgments. First, institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life," and second that unnecessary

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[4] 42 U.S.C. § 12101(b)(1).

[5] 42 U.S.C. § 12132.

[6] *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 599-600 (1999). Individuals who are at serious risk of unnecessary institutionalization need not wait until they are admitted to an institution before bringing a claim under *Olmstead*. *Waskul v. Washtenaw Cnty. Com'ty Mental Health*, 979 F.3d 426, 460-61 (6th Cir. 2020) (collecting cases); *Davis v. Shah*, 821 F.3d 231, 263 (2d Cir. 2016); *Pashby v. Delia*, 709 F.3d 307, 322 (4th Cir. 2013); *Radaszewski ex rel. Radaszewski v. Maram*, 383 F.3d 599, 608, 615 (7th Cir. 2004); *Townsend v. Quasim*, 328 F.3d 511, 515, 520 (9th Cir. 2003); *Fisher v. Okla. Health Care Auth.*, 335 F.3d 1175, 1181-82, 1184 (10th Cir. 2003); *J.P. ex rel. Ogden v. Belton 124 School Dist.*, No. 20-cv-189, 2020 WL 3643131, at *2 (W.D. Mo. July 6, 2020).

Other forms of prohibited discrimination by a public entity include limiting a person's "enjoyment of any right, privilege, advantage, or opportunity" provided by the public entity and enjoyed by others who receive it, 28 C.F.R. § 35.130(b)(1)(vii); using methods of administration that have the effect of discriminating, *id.* § 35.130(b)(3); or imposing a surcharge on the receipt of public services. *Id.* § 35.130(f).

[7] *Olmstead*, 527 U.S. at 587.

[8] 28 C.F.R. § 35.130(d).

[9] 28 C.F.R. pt. 35, app. B, at 703 (2023).

[10] 42 U.S.C. § 12101(a).

confinement "severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."[11] In *Olmstead* the Supreme Court found discriminatory "dissimilar treatment" exists when people with disabilities must "relinquish participation in community life they could enjoy given reasonable accommodations," to get needed services, while people without disabilities "can receive the medical services they need without similar sacrifice."[12]

Public entities are required to "make reasonable modifications to policies, practices, and procedures when the modifications are necessary to avoid discrimination on the basis of disability," unless doing so would "fundamentally alter the nature of the service, program, or activity."[13] Even when a State relies on private entities to deliver some of its services, it is still ultimately responsible under the ADA.[14] If a state fails to reasonably modify its service system to provide care in the most integrated setting appropriate, it violates Title II of the ADA.[15] Expansion of existing services is a reasonable modification.[16] A public entity may show that modifications would be fundamental alterations if the public entity has a "comprehensive, effectively working plan for placing qualified persons…in less restrictive settings." [17]

MISSOURI'S SYSTEM FOR SERVING ADULTS WITH MENTAL HEALTH DISABILITIES

A. Three State agencies share responsibility for serving adults with mental health disabilities

There are three agencies in Missouri primarily responsible for serving or coordinating services for people with mental health disabilities living in the community and in nursing facilities:

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[11] *Olmstead*, 527 U.S. at 600-01.

[12] *Id.*

[13] 28 C.F.R. § 35.130(b)(7).

[14] The ADA's integration mandate applies where a public entity administers its programs in a way that leads to unjustified segregation of people with disabilities. *See* 28 C.F.R. § 35.130(d). A public entity may violate the ADA's integration mandate when it: (1) directly or indirectly operates facilities and or/programs that segregate people with disabilities; (2) finances the segregation of people with disabilities in private facilities; and/or (3) through its planning, service system design, funding choices, or service implementation practices, promotes or relies upon the segregation of people with disabilities in private facilities or programs. 28 C.F.R. § 35.130(b)(1)-(2).

[15] *Olmstead*, 527 U.S. at 607; 28 C.F.R. § 35.130(b)(7).

[16] *See, e.g., Pashby*, 709 F.3d at 323-24; *Radaszewski*, 383 F.3d at 609 ("[A] State may violate Title II when it refuses to provide an existing benefit to a disabled person that would enable that individual to live in a more community-integrated setting."); *Messier v. Southbury Training Sch.*, 562 F. Supp. 2d 294, 344-45 (D. Conn. 2008); *Disability Advocates, Inc. v. Paterson*, 598 F. Supp. 2d 289, 335-36 (E.D.N.Y. 2009) ("Where individuals with disabilities seek to receive services in a more integrated setting—and the state *already provides* services to others with disabilities in that setting—assessing and moving the particular plaintiffs to that setting, in and of itself, is not a 'fundamental alteration.'").

[17] *Olmstead*, 527 U.S. at 605-06; *Brown v. District of Columbia*, 928 F.3d 1070, 1084 (D.C. Cir. 2019).

1. The Department of Health and Senior Services (DHSS): DHSS licenses and oversees about 500 nursing facilities located across the State. DHSS's Adult Protective Services (APS) investigates claims of abuse and neglect of adults. Based on APS investigations, DHSS files petitions—formal requests sent to a judge—to place adults with mental health disabilities under guardianship.

2. The Department of Mental Health (DMH): DMH, through its Division of Behavioral Health, designs, oversees, and provides targeted funding for, the State's mental health services. DMH also files petitions to put adults with mental health disabilities under guardianship: and

3. The Department of Social Services (DSS): DSS houses Missouri's Medicaid agency, MO HealthNet. MO HealthNet funds both nursing facility stays and Medicaid-billable community-based mental health services.

All three agencies are involved in running Missouri's Preadmission Screening and Resident Review (PASRR) system. PASRR is used to determine the appropriateness of nursing facilities for people with mental health disabilities.

B. Missouri oversees and funds a network of community-based mental health providers

Missouri primarily provides community-based mental health services to Medicaid-enrolled individuals through 27 regional providers who contract with and are overseen by DMH. DMH also contracts with 11 affiliated providers who offer additional services in each region, and with two organizations that work with the regional providers to answer crisis calls. All of the regional providers and three of the affiliated providers are Certified Community Behavioral Organizations (CCBHOs).[18] CCBHOs get a daily rate for services they provide to people with mental health disabilities and are required to offer a minimum bundle of services defined, in part, by the State.

Key services that enable community integration and are available through some or all of these providers include: housing services, Assertive Community Treatment, supported employment, peer support, crisis services, and case management.[19] Assertive Community Treatment (ACT)

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[18] CCBHOs are also called Certified Community Behavioral Health Clinics (CCBHCs). CCBHOs must provide (or arrange for a Designated Collaborating Organization to provide) a set of required services. They are also expected to quickly connect people to those services. *See Certified Community Behavioral Health Clinics (CCBHCs)*, Substance Abuse and Mental Health Services Administration [SAMHSA], https://perma.cc/4UNY-2RWH (Apr. 24, 2023). CCBHOs get Medicaid payments for the services they provide using a bundled daily Prospective Payment System that accounts for the cost of providing services. *Certified Community Behavioral Health Clinics Demonstration Program: Report to Congress, 2018*, Dep't of Health & Human Servs., Office of the Assistant Sec'y for Planning & Evaluation (Sept. 2019), https://perma.cc/MJ3Y-L4L3. Missouri was one of the first states to begin transitioning to CCBHOs. *Certified Community Behavioral Health Clinics (CCBHCs)*, Mo. Dep't of Mental Health, https://perma.cc/BF3Q-M5VQ (last visited Jan. 5, 2024). For State Fiscal Year 2023, the daily rate for CCBHOs providing community-based mental health services to an individual was between $204.80 to $304.91.

[19] Some in the State use "Community Psychiatric Rehabilitation" or "CPR" as a shorthand for case management. CPR is also an umbrella term that can describe the array of mental health services

and housing services are the two services most needed by adults with mental health disabilities to prevent nursing facility admission and support transition back to the community in Missouri. ACT is an intensive service where a team of healthcare workers support an individual by providing them mental health treatment and services to help with housing, employment, and other basic needs. Services are provided in the person's home and in the community.[20] Housing services, including Permanent Supportive Housing, are services to help an individual with getting and maintaining a place to live.[21] These services enable people who might otherwise be unnecessarily institutionalized to live, work, and participate in their communities. Missouri acknowledges that this array of services can prevent unnecessary institutionalization. But it does not ensure people are connected to these supports to prevent nursing facility admissions or to enable transitions out of nursing facilities.

C. Missouri uses guardianships for people with mental health disabilities

Guardianship is a process in which a court appoints someone to make decisions for a person found to be incapacitated. This often includes decisions about the person's health and where to live. When an adult with a mental health disability is not following the recommended treatment or when there is difficulty identifying services for them, a frequently used strategy in Missouri is to petition for guardianship and/or conservatorship. An appointed guardian then manages care for the person and has authority to make decisions for them. The guardian may be a family member or public administrator. Public administrators are county officials that are appointed as guardians for adults when there is no adult relative suitable to the court and willing to serve as guardian.[22] Unless a request to terminate a guardianship is made to the judge and the judge grants it—an event that is rare in Missouri—guardianships run until the person under guardianship dies. The result is that thousands of adults with mental health disabilities in Missouri have been placed under and stay in guardianships.

Guardianships in Missouri tend to permit the guardians to make all decisions for the individual under guardianship, including choices about where to live. According to Missouri law, if a person is found to lack the capacity necessary to manage their "essential requirements for food, clothing, shelter, safety or other care so that serious physical injury, illness, or disease is likely to occur" a guardian or limited guardian may be appointed.[23] If a person is found to lack the capacity necessary to manage their "financial resources" a conservator or limited conservator

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provided by DMH-contracted providers to people with mental health disabilities. These programs are coordinated through case management, which is one of the services under the CPR umbrella.

[20] *Assertive Community Treatment: Building Your Program*, SAMHSA 5-6 (2008), https://perma.cc/B38V-V42H.

[21] *Permanent Supportive Housing*, SAMHSA https://perma.cc/K5H3-BBY4 (last visited Jan. 5, 2024).

[22] *See* Mo. Rev. Stat. § 475.050(2) (2022) ("The court shall not appoint an unrelated third party as a guardian or conservator unless there is no relative suitable and willing to serve or if the appointment of a relative or nominee is otherwise contrary to the best interests of the incapacitated or disabled person."); Mo. Rev. Stat. § 473.730 (2022) (defining public administrators). All public administrators in Missouri are elected, with the exception of Jackson County, St Charles County, and the City of St Louis where they are appointed by a court. Mo. Rev. Stat. § 475.050(2) (2022).

[23] *See* Mo. Rev. Stat. § 475.075(11) (2022).

may be appointed.[24] Full guardianships together with full conservatorships—where the person loses all of their decision-making rights—are used more frequently than limited guardianships and/or conservatorships in Missouri. Because guardianships and conservatorships usually go together for this population, in this report, the term guardianship will be used to refer to both guardianship and conservatorship.

PEOPLE WITH MENTAL HEALTH DISABILITIES ARE UNNECESSARILY PLACED IN NURSING FACILITIES AND UNDER GUARDIANSHIPS

Thousands of adults with mental health disabilities in Missouri are institutionalized in nursing facilities that segregate them from their communities. Many are also under guardianship with public administrators, who have reluctantly become a key part of Missouri's system for serving adults with mental health disabilities. These adults often are young, have lower physical care needs, and spend longer in nursing facilities than nursing facility residents without mental health disabilities. A significant proportion of these adults are concentrated in a small number of Missouri's nursing facilities. Despite this, adults with mental health disabilities are appropriate for and do not oppose receiving community-based mental health services.

A. Nursing facilities are institutions that segregate adults with mental health disabilities from the community

Missouri's nursing facilities are segregated institutions. They are highly restrictive and controlled settings that isolate and segregate residents by severely limiting or entirely cutting off their relationships with loved ones and their community, and preventing them from interacting with non-disabled people. This is especially evident at nursing facilities where many of the residents have a mental health disability. Nursing facility stays also limit residents' ability to pursue an education and jobs and keep them from participating in cultural events. All of these are hallmarks of a segregated institution.[25]

People with mental health disabilities living in nursing facilities are restricted from engaging in their communities. "My son had a life before they took him there and now, he has nothing," said the mother of Kelvin, an adult with a mental health disability currently living in a nursing facility. Kelvin loved being outside and wanted to be a forest ranger. Now he lives in a locked unit of a nursing facility where he has only recently started being allowed to go outside. Many nursing facilities are locked, and some have locked wings segregating adults with mental health disabilities away from other residents. Residents in these locked facilities or units, like Kelvin, generally cannot leave without permission. Ciara, who lived at three different nursing facilities, said at one facility she couldn't even travel to activities in another building within the nursing facility. Elijah, who has spent 11 years in nursing facilities, said at some facilities he wasn't even

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[24] *Id.*

[25] *See Thorpe v. District of Columbia*, 303 F.R.D. 120, 125 n.7 (D.D.C. 2014) (in a matter involving an *Olmstead* claim for unnecessary segregation in nursing facilities, identifying cases that brought similar claims); *Conn. Office of Prot. & Advocacy for Persons with Disabilities v. Connecticut*, 706 F. Supp. 2d 266, 276-277 (D. Conn. 2010) (denying motion to dismiss *Olmstead* claim in case involving plaintiffs confined to nursing facilities); *Joseph S.*, 561 F. Supp. 2d at 286-87, 293 (denying motion to dismiss *Olmstead* claim where the defendant funded nursing facility placements); *see also* 42 U.S.C. § 1395i-3(a) (the Social Security Act defining skilled nursing facilities as institutions).

allowed to leave his assigned hallway. One nursing facility told us it only allows residents to go outside with guardian authorization. Alan missed his daughter's graduation and did not get to see the birth of his "grandbaby." The nursing facility also keeps him from running simple errands: "I ask if I can go to [the] store, and they don't let me," he said.

Residents also have difficulty communicating with loved ones. At one facility we visited, residents can only use the phone on Wednesdays during a specific hour and a half block. Calls can only last up to 10 minutes, and people can only make calls with guardian authorization.[26] A resident at another nursing facility said she also has limited availability to use the phone and is unable to call in for prayer with her community. Often people cannot see their families in person, because adults with mental health disabilities are frequently placed in facilities that are far from their homes and loved ones.

Several people we spoke to explicitly compared nursing facilities to jails and prisons due to the lack of freedoms available to residents. Pamela's mother said her daughter told her living at a nursing facility was "like being held in prison against her will." Nursing facility residents with mental health disabilities have little choice over their day-to-day lives, including their hygiene, activities, food, clothes, and even where they can physically go within the nursing facility. Residents have little privacy, with most facilities placing them in shared rooms.[27] Residents' behaviors are closely monitored and controlled. They must obey facility staff's instructions, or face punishments. Punishments include losing access to the phone or internet, being restricted to their room, being moved to a more restrictive area, or not being allowed to smoke.

Legal Guardian Imposed Limitations
• No telephone privileges • No mail • Resident not allowed to go off the unit
• Resident allowed to go off the unit for 20 minutes 3 times a day • No phone or mail restrictions
• Resident is allowed to go outside 1 hour per day • Resident not allowed to get phone calls from mother
• -OSP- with approved responsible party • Resident only allowed to call Legal Guardian on Fridays • Resident may smoke independently
• Resident may go to store 3 times per week
• Resident may walk to gas station 3 days per week with staff • Resident own Responsible Party

When a person with mental health disabilities is under a guardianship, their experience in a nursing facility is even more isolating. Nursing facilities afford guardians the option to limit a wide variety of activities, including activities (like their communications) that Missouri law does not allow guardians to restrict. The chart on this page is from a nursing facility document that shows the limitations that the facility allows guardians to impose. Angela, a nursing facility resident under a guardianship, told us: "I think prisoners have more rights than a person under guardianship has. Anything I do or have pleasure in, like smoking, can be taken away [at] the whim of my guardian."

[26] This is despite a Missouri statute that expressly provides people under guardianship the right to "communicate freely and privately with family, friends, and other persons other than the guardian[.]" Mo. Stat. Ann. § 475.361.

[27] DMH recognizes that significant numbers of shared rooms are associated with more restrictive settings.

B. Thousands of adults with mental health disabilities are living in Missouri's nursing facilities

Missouri has a high proportion of adults with mental health disabilities in its nursing facilities and relies on nursing facilities for people with mental health disabilities to a greater extent than all but a few states. It also has a few dozen facilities with highly concentrated populations of people with mental health disabilities. These people are on average younger, have fewer nursing care needs, and stay in nursing facilities longer, than other nursing facilities residents. The facts show that Missouri is using nursing facilities to serve the gap created by the inadequate community-based mental health services in the State.

Missouri places a higher percentage of adults with bipolar disorder or schizophrenia in nursing facilities than almost any other state. From 2011 to 2021, Missouri nursing facilities consistently had between the second and third highest percentage of residents with schizophrenia or bipolar disorder in the nation.

3,289

Adults with mental health disabilities in Missouri's nursing facilities for 100+ days, excluding those with Alzheimer's or dementia

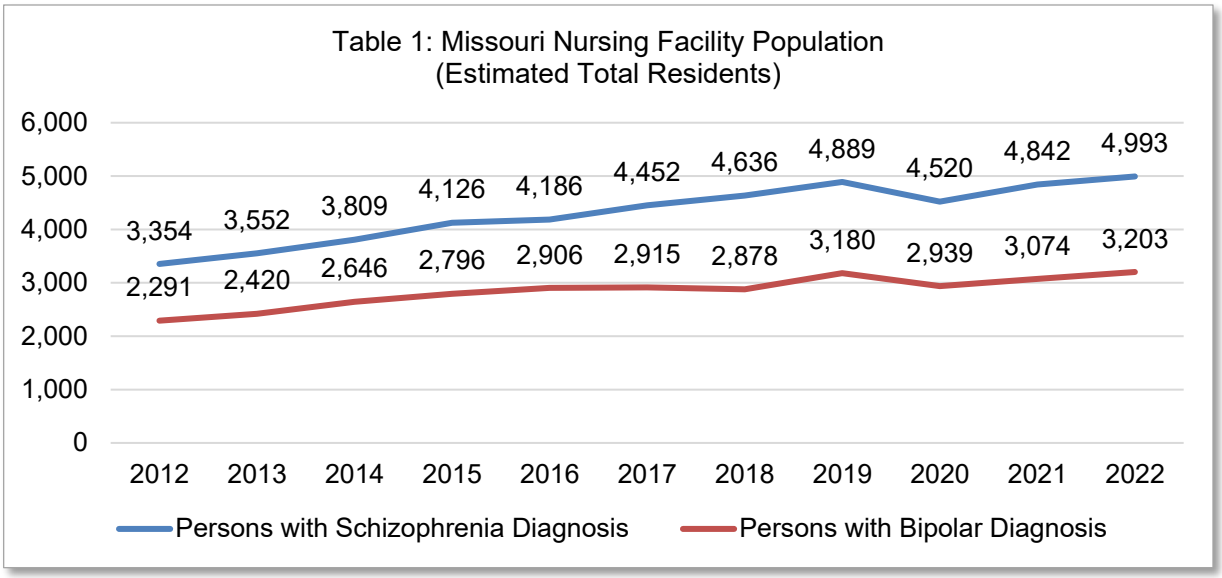
In March 2023, there were 3,289 Medicaid-eligible adults with mental health disabilities[28] in Missouri's nursing facilities who had been there for at least 100 days[29] and who did not have a co-occurring diagnosis of Alzheimer's or dementia.[30] Without excluding those with Alzheimer's and dementia, there were 6,179 such adults.

[28] To calculate this number, we considered a person to have a mental health disability if they were in at least one of these four categories: 1) diagnosed with schizophrenia; 2) diagnosed with bipolar disorder; 3) entered the nursing facility from a psychiatric hospital; or 4) was found to have a "serious mental illness" through the PASRR process. PASRR is explained on pages 35-36 below.

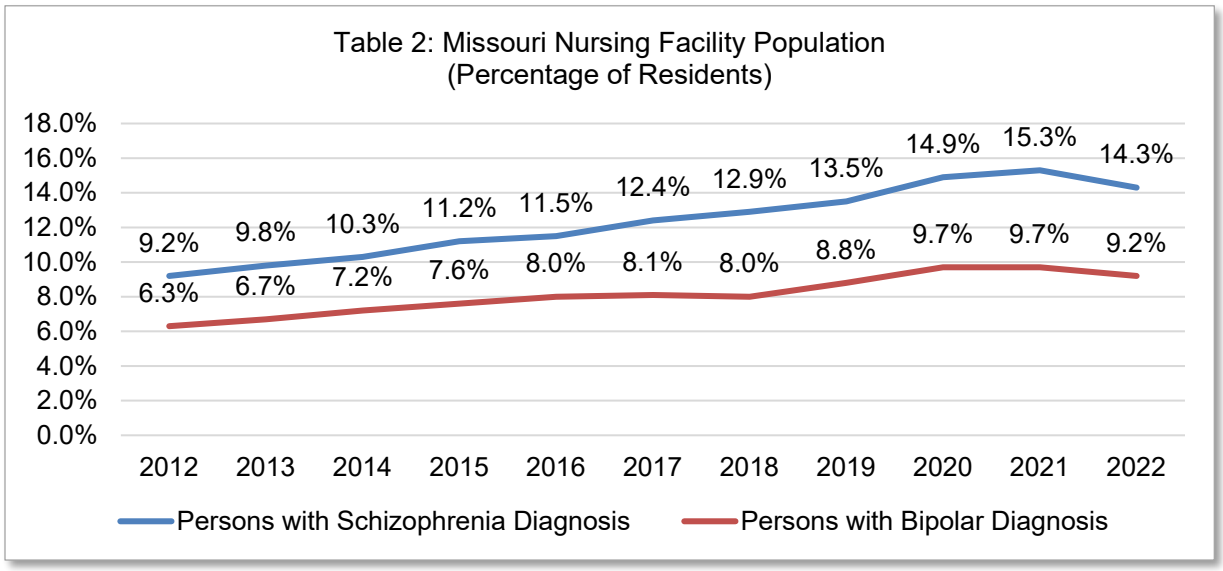
[29] Some people enter nursing facilities for short, rehabilitative stays. A short-term stay is generally considered to be 100 days or less.

[30] Given the differences in service needs that people with Alzheimer's or dementia may have from those without co-occurring diagnoses, our investigation focused on people with mental health disabilities who do not also have those co-occurring diagnoses. This does not mean that adults with Alzheimer's or dementia who have mental health disabilities are categorically unable to benefit from the remedies described on pages 39-42 below.

The number of adults with mental health disabilities in nursing facilities has steadily increased just about every year since 2012. For example, Table 1 below shows the growth in the population of adults with just bipolar disorder and schizophrenia diagnosis—two diagnoses that are tracked in nursing facility data nationally. In 2022, Missouri institutionalized around 49% more people with a schizophrenia diagnosis and around 40% more people with a bipolar disorder diagnosis in nursing facilities than it had in 2012. In a similar time period (April 1, 2010 to July 1, 2022) Missouri's population grew by only 3.1%.



While the population of nursing facility residents with mental health disabilities has increased, Missouri has decreased its population of nursing facility residents without mental health disabilities. Because the total nursing facility population has been stable through this time, this has led to an increase in the proportion of residents who have mental health disabilities since 2011. For example, Table 2 below shows how the proportion of adults with schizophrenia or bipolar diagnoses in Missouri nursing facilities has grown almost every year over the last ten years, mirroring the trend seen in Table 1.



1. **Adults with mental health disabilities are concentrated in a small number of nursing facilities**

Most adults with mental health disabilities living in Missouri's nursing facilities are concentrated in a small number of nursing facilities. As of March 2023, 50% of nursing facility residents with mental health disabilities (excluding those with a co-occurring diagnosis of Alzheimer's or dementia) who had been in the nursing facility 100 days or more lived in just 39 of Missouri's 500 nursing facilities.[31] The map on this page shows the 10 High Volume Facilities with the highest number of these residents.[32]

In 2021 at 10 of the 39 High Volume Facilities, adults with bipolar disorder or schizophrenia diagnoses were between 82% and 90% of the total resident population. And High Volume Facilities are large. In 2023, the total number of residents at these facilities ranged from 47 to 225, with an average of 95 residents. Staff at High Volume Facilities told us their nursing facilities specialize in adults with mental health disabilities. One called their nursing facility a "psych facility."

2. **Adults with mental health disabilities generally have lower nursing care needs than other people in Missouri's nursing facilities**

Many nursing facility residents in Missouri have low physical care needs. In a 2019 report from Missouri's Department of Social Services, the State acknowledged it had a significantly higher

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[31] We refer to these 39 nursing facilities as the High Volume Facilities. Nursing facility residents with mental health disabilities who are Black are more likely than their white counterparts to live in a High Volume Facility.

[32] One of the High Volume Facilities on the map, Northview Village, closed abruptly in December 2023, displacing 170 residents. A significant number of the St. Louis facility's residents had a mental health disability. *See* Jim Salter, Heather Hollingsworth, *Largest Nursing Home in St. Louis Closes Suddenly, Forcing Out 170 Residents*, Associated Press (Dec. 18, 2023), https://perma.cc/4JXU-WXGW. News reports at the time indicated many residents were abruptly moved to other nursing facilities, however at least one person was unaccounted for several weeks after the closure. *Id.*, Anthony Raphael, *The Aftermath of a Nursing Home Closure: A Search for Frederick Caruthers*, Medriva (Jan. 5, 2024), https://perma.cc/6GTL-V7D9.

Another one of the High Volume Facilities on the map, Levering Regional Health Care Center, announced its closure in May 2024. Zach Richardson, *Levering Regional Health Care Center announces permanent closure*, KHQA (May 15, 2024), https://perma.cc/SK6D-CCEF. *See* footnote 62 below.

percentage of nursing facility residents with low care needs (24% vs. the national average of 11%) than other states.[33] The State recognized that this suggested there were opportunities for more nursing facility residents to be served in the community.[34] This is still the case: according to a report based on 2021 data, Missouri had a higher percentage of nursing facility residents with low care needs (25.3%) than any other state.[35] The national average in 2021 was 8.8%.[36]

Adults with mental health disabilities are even more likely to have low physical care needs than other nursing facility residents in Missouri. We reviewed the records of a sample of adults with mental health disabilities in nursing facilities across the State. Less than half of the people we reviewed needed personal care or help with daily living, despite living in a nursing facility. The majority of people with mental health disabilities (and without dementia or Alzheimer's) in nursing facilities needed no help with activities like eating, toilet use, transferring, and bed mobility. Those living in High Volume Facilities were significantly less likely to need personal care or help with daily living than people in other facilities. The fact that adults with mental health disabilities in nursing facilities in Missouri tend to have relatively low need for nursing care highlights why nursing facilities are not appropriate for these individuals.[37]

3. Adults with mental health disabilities are generally younger than other people in Missouri's nursing facilities

Many adults with mental health disabilities in nursing facilities are young. As shown in the bar graph on the next page, 49% of adults with mental health disabilities in Missouri nursing facilities are under the age of 65 more than two and a half times the national rate (17.59%).[38] The average age in the sample of adults with mental health disabilities we reviewed was 53; by contrast, the average age all of the State's nursing facility residents is 75. The average age of residents with mental health disabilities in the 10 High Volume Facilities with the largest numbers of residents with mental health disabilities was 47. We spoke with over two dozen people with mental health disabilities, or their loved ones, who were first admitted to a nursing facilities in their 20s and 30s. "To be in a nursing home at 33, I could not believe that," one told us.

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[33] *Rapid Response Review – Assessment of Missouri Medicaid Program Final Report,* Mo. Dep't of Social Servs. 44 (Feb. 11, 2019), https://perma.cc/W4X5-B6V6.

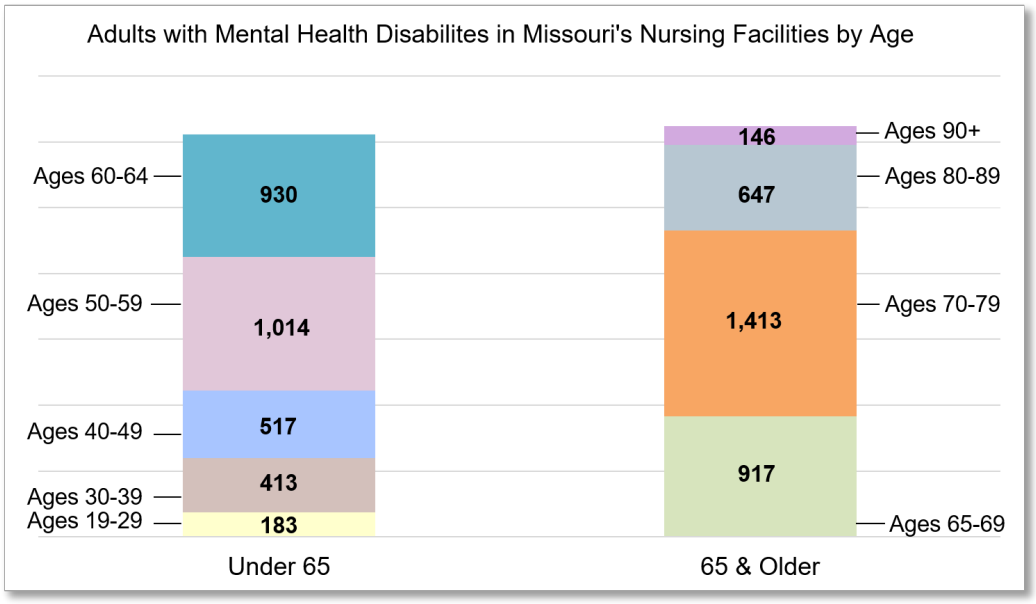
[34] *Id.*

[35] *NH Residents with Low Care Needs,* AARP, (2023), https://perma.cc/79ET-4EEU.

[36] *Id.*

[37] A study reviewing research from 2000 to 2020 on nursing facility care for adults with mental health disabilities found that: "[n]ursing homes (NH) and other institutional-based long-term care settings are not considered an appropriate place for the care of those with serious mental illness, absent other medical conditions or functional impairment that warrants skilled care." *See* Taylor Bucy, et al. *Serious Mental Illness in the Nursing Home Literature: A Scoping Review*, Gerontology and Geriatric Medicine (May 9, 2022), *available at* https://journals.sagepub.com/doi/full/10.1177/23337214221101260.

[38] This includes adults with mental health disabilities who have co-occurring diagnoses, such as Alzheimer's and dementia.



4. Adults with mental health disabilities generally stay institutionalized longer than other people in Missouri's nursing facilities

Despite their relative youth and low physical care needs, adults with mental health disabilities stay institutionalized for significant lengths of time. On average, adults with mental health disabilities have been in their current nursing facility for nearly 3.5 years. Because this data does not include time spent at any previous nursing facilities, it is likely an undercount. We spoke with over two dozen people with mental health disabilities, or their loved ones, who transferred from one nursing facility to another. At least five of them had spent more than 9 years in nursing facilities, with one spending around 18 years.

Public administrators, loved ones, and other stakeholders have long noticed what the data confirms: Adults with mental health disabilities, including young people, are being placed in and staying in nursing facilities not for skilled nursing care, but because of their mental health disabilities.

C. Guardianship is a key feature of the State's system of caring for adults with mental health disabilities and leads to their unnecessary segregation in nursing facilities

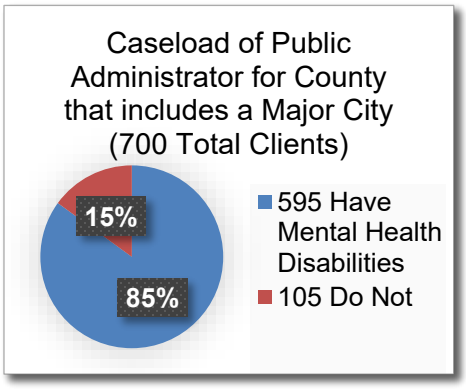
The State routinely relies on guardianships, particularly under public administrators, for adults with mental health disabilities who are harder to engage in treatment.[39] And guardianship, in turn, serves as a pipeline to unnecessary institutionalization.

[39] The guardianship and conservatorship system in Missouri is a public "service, program, or activity" covered by Title II of the ADA. *See Bahl v. Cty. Of Ramsey*, 695 F.3d 778, 787 (8th Cir. 2012) (citations omitted) (interpreting the "services, programs, or activities" language in the ADA to encompass "anything a public entity does."); *see also* 28 C.F.R. Pt. 35, App. B ("title II applies to anything a public entity does.").

Involuntarily committing a person to a psychiatric hospital is a severe restriction of their liberty. As a result, to commit a person longer than 96 hours in Missouri, the judge must find by clear and convincing evidence that the person "presents a likelihood of serious harm" to themself or others.[40] Any further commitment beyond 21 days requires a new hearing.[41] In contrast, people under guardianship can have their liberty restricted in almost the same manner—by being locked in a nursing facility and forced to take medication against their will—indefinitely. This is because, in contrast to commitments, there is no requirement for automatic additional hearings to re-evaluate the need for guardianship.[42] Guardianships in Missouri are imposed by a judge, with the same "clear and convincing evidence" requirement as involuntary commitments.[43] But attorneys report that most guardianship petitions are not challenged and note that procedural protections are not meaningfully implemented. More than 60% of the nursing facility residents in the sample we reviewed have guardians, and of those individuals nearly all were placed in the facilities by their guardians. Less than half reported receiving any kind of community-based mental health services before their guardian placed them in a nursing facility.

1. Thousands of adults with mental health disabilities are under guardianship in Missouri

In November 2021, a public administrator testified before the Missouri House Committee on Mental Health Policy Research that the percentage of people under guardianship with her office who had "mental health issues and concerns" had increased from about 20% in January 2003 to about 65% in November 2021. Data from the Missouri Association of Public Administrators (MAPA) confirm this is a statewide trend. Based on a 2020 survey of at least 92 public administrators, MAPA found that adults with a primary diagnosis of mental illness or behavioral health issues constituted 33% of respondents' caseloads. This means over 3,000 adults with mental health disabilities are under guardianship with a public administrator. In some counties, the trend is even more striking. Public administrators told us that between 50 to almost 100% of their caseloads are people with mental health disabilities. A public administrator from a county that includes a major city shared their estimated caseload with DOJ, displayed on this page as a pie chart. Public administrators' "[c]aseloads are evolving to include a greater number of cases with younger individuals,



[40] *See* Mo. Rev. Stat. § 632.330, 632.335.

[41] *See* Mo. Rev. Stat. § 632.340.

[42] *See* Mo. Rev. Stat. §475.082. Although guardianships require an annual review of documentation, no hearing is required.

[43] *See* Mo. Rev. Stat. §§ 475.075(9), (10).

including an increase in those with mental and behavioral health needs."[44]

2. The State seeks guardianships directly and promotes their use

Despite acknowledging that guardianships are "very restrictive" and not a substitute for mental health care, the State itself files guardianship petitions with the purpose of involuntarily enrolling people with mental health disabilities in care. It does this primarily through DMH, DHSS Adult Protective Services (APS), and the Missouri Attorney General's Office. From July 2018 to May 2023, Missouri filed petitions to place at least 360 adults with mental health disabilities under guardianship.[45]

The State also promotes the use of guardianship by failing to (1) hold providers responsible for engaging people in intensive community-based services and (2) train its staff and the staff of providers it contracts with on alternatives to guardianship approved under Missouri law, like Supported Decision-Making. Supported Decision-Making is a flexible tool that allows a person with a disability to appoint people they trust to give them advice and support them in making their own decisions.[46] Instead, the State's website lists guardianship as a tool for people with mental health disabilities.

3. Guardianships are the primary tool in Missouri for serving people who have not been easy to engage in treatment

Missouri files guardianship petitions for people who are considered noncompliant with treatment. DMH and APS staff prepare summaries describing why guardianship is recommended in each case. We reviewed the summaries for about 100 of these people. The documents highlight the State's use of guardianship as the primary response to people who do not engage in treatment. These summaries, along with the statements of a Missouri state official, confirm that Missouri is filing guardianships without first providing intensive community-based services like ACT and peer support—which could eliminate the need for a guardianship—and that Missouri is not considering other alternatives like Supported Decision-Making, before resorting to guardianship. Loved ones and providers struggling to connect adults with mental health disabilities to needed services and supports are following the State's example. A common approach in Missouri is, thus, a guardianship and nursing facility combination that forces people into restrictive, segregated treatment settings. Combining guardianships and nursing facility placement creates the functional equivalent of involuntary and indefinite commitment.

In a large majority of the summaries for cases initiated by the State that we reviewed, noncompliance with medication and treatment was noted as a primary reason why a guardianship was needed. For example, Missouri's files explained that Lilian does not like her medications because they make her drowsy and lethargic. The APS caseworker did not

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[44] Mo. Ass'n of Pub. Admins., *Missouri Public Guardianship Report*, Mo. Dep't of Mental Health 17 (Apr. 20, 2020), https://perma.cc/WDF4-8SYY.

[45] This does not include petitions filed for adults who are aging out of foster care or people who have been found "not guilty by reason of insanity" or "incompetent to stand trial" in a criminal case.

[46] Missouri's Supported Decision-Making law is described below on page 20.

recommend that Lilian's prescriber work with her to find medications she is comfortable with, or otherwise engage her in treatment to promote recovery. Instead, the APS worker recommended a guardianship because she was concerned Lilian "will get off her medication again and put herself in dangerous situations again."

Though some case summaries state that the adult with a mental health disability had been connected to a DMH contracted provider before, they did not indicate that the State had worked with providers to identify other community-based services that might meet the individual's needs, or held providers responsible for inadequate intensity of services. This was confirmed by a State official who said APS does not require a person with a mental health disability to be connected to services before a guardianship petition can be filed and does not have a mechanism for working with DMH to hold providers accountable. In one example, Missouri filed a guardianship petition for a person the APS worker acknowledged had not been connected to needed community-based services, including crisis services. Rather than holding its provider accountable for failing to respond to the APS caseworker's requests for services and working with the provider to ensure Julia got intensive services in the community, the State filed for guardianship. The guardian then approved Julia's placement in a nursing facility.

Studies and experience show that engaging people who are skeptical of or resistant to mental health treatment requires building a strong therapeutic relationship, actively involving the person in decisions about their own care, providing practical help with things like housing and finances, and not focusing solely on medication adherence. As one state official admitted, Missouri has services that, if appropriately and consistently provided, could achieve this goal.[47] But guardianship is often used instead. For example, one woman we met entered guardianship and a nursing facility in her early 20's after she did not get assertive engagement. Pamela is a 31-year-old whose mother describes her as "amazing, bright, funny, gifted." Pamela likes music, dance, and gymnastics. But she has not enjoyed these hobbies for 12 years because Missouri failed to provide her the services she needed to stay in the community. This led her family to turn to guardianship and her public administrator to place her in a nursing facility. Before her institutionalization, Pamela cycled in and out of psychiatric hospitals and at times did not want to take medication. Her family had trouble getting her connected to mental health care. As a result, when she was 21, her father filed a petition to have her placed under guardianship and the public administrator was appointed. Instead of identifying a provider who would assertively engage Pamela to encourage her participation in treatment, the public administrator placed Pamela in a nursing facility.

4. Heavy caseloads lead guardians to resort to using nursing facilities rather than identifying and connecting people to community-based alternatives

The Missouri Association of Public Administrators have identified one guardian for every 20 people under guardianship as the national standard caseload for professional guardians.[48] Yet

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[47] A Missouri state official agreed community-based mental health services offered by DMH's providers could help someone at risk of guardianship. The official said DMH contracted providers should make additional efforts to engage those individuals, including by sending staff out to find and connect them to services, before resorting to guardianship.

[48] Mo. Ass'n of Pub. Admins., *Missouri Public Guardianship Report*, Mo. Dep't of Mental Health 4 (Apr. 20, 2020), https://perma.cc/WDF4-8SYY.

public administrators in Missouri average a caseload of 91 people, and more than one third of public administrators work without staff.[49] The Missouri Association of Public Administrators calls some public administrators' caseloads "dangerously high." For example, one office manages over 715 cases between four staff members. Another public administrator, who said she has begged for more full time staff, told us she was so frustrated recently she tried to resign. Two public administrators declined interviews with us due to being overburdened with their workload.

High caseloads and low staffing mean little time to support each of the people under guardianship. We spoke with nursing facility residents who told us they went years without seeing their guardians and that guardians do not return phone calls, or are otherwise unavailable to speak with them. Angela, who lives in a nursing facility, told us that she could not reach her public administrator directly and that at one point her phone number was blocked by the administrator's office. Orlando's loved one told us Orlando has never had a face-to-face conversation with his public administrator and he is only allowed to call her office on Thursdays. He has been at the nursing facility his guardian placed him in for two and half years. A public administrator lamented: "These people deserve so much more than what we give them."

High caseloads and low staffing also create an incentive to turn to low maintenance options like nursing facilities. For example, one public administrator admitted she hates keeping so many of the people in her care "locked up" but she does not have the resources to manage care for people in the community. Multiple State officials explained that public administrators may be likely to turn to nursing facilities because many are locked facilities and provide the public administrator with peace of mind. This is regardless of the actual safety or therapeutic value. One of the State officials said: "I don't know if [the individuals living in the nursing facilities] are safer. I can't really say that. But . . . the guardian thinks they are safer because they cannot leave."

As a result, in Missouri, guardianship for people with mental health disabilities and placement in nursing facilities go hand in hand. When asked how many residents have a guardian, a nursing facility administrator told us: "It's easier to say how many don't have guardians." Sixty-two percent of the adults with mental health disabilities living in nursing facilities interviewed for our review had a guardian. Of those, 80% had a public administrator as their guardian. At the High Volume Facilities where adults with mental health disabilities are highly concentrated, that number was even higher. Seventy-three percent of the residents we interviewed had a guardian, and of those, 84% had a public administrator as guardian.

Not only is Missouri aware of public administrators' reliance on nursing facilities, it also actively pursues guardianships so that the guardians will place adults with mental health disabilities, who would otherwise not consent to it, in nursing facilities. In several APS summaries, the ability to place or keep someone in a nursing facility against their will was listed as a reason why a guardianship was needed. The image below is an example of one such court summary. A State official confirmed that the State uses guardianships "probably pretty often" to enable placement in and continued stay in nursing facilities for people with mental health disabilities.

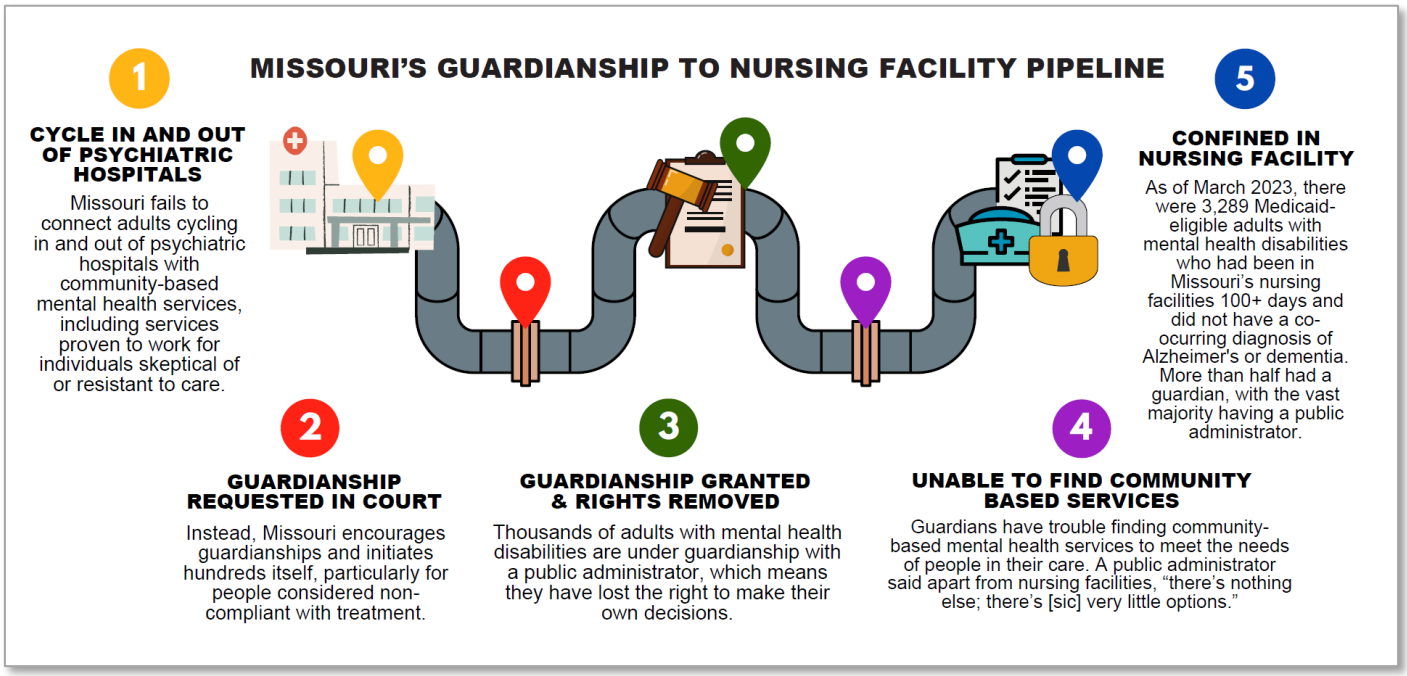
[49] *Id*.

Department of Health & Senior Services
Division of Senior Services

1704.48
Exhibit A

3. In your opinion, what would be the consequences if the guardianship/conservatorship were delayed?
[redacted] is currently in a skilled nursing home, however with [redacted] being her own guardian she could leave at any time which would be detrimental to [redacted].

The medical director of a CCBHO described the pathway many adults with mental health disabilities follow to enter nursing facilities this way: They cycle in and out of psychiatric hospitals until they are appointed a guardian. Once they are appointed a guardian, "[t]hen that's kind of a sentence to be locked in a [nursing facility]," she said. The infographic below provides a visualization of the guardianship to nursing facility pipeline that the State has encouraged and participated in.



5. Adults with mental health disabilities living in Missouri's nursing facilities generally do not need guardianships

Guardians can and do require adults with mental health disabilities to reside in Missouri's nursing facilities. They also can and do block access to community-based services for adults with mental health disabilities in Missouri's nursing facilities. They exercise this control even though nearly all of the adults in our sample who were under guardianship were able to "receive

and evaluate information" and "communicate decisions" when we met them.[50] Nearly all of them understood our questions and were able to communicate their preferences and hopes for the future; and explain the reasoning behind their preferences. More than half identified the areas where they needed support to live in the community and manage their own affairs and what kind of support they'd like to get, like help with groceries and medications. In the experience of our experts, people with similar symptoms and treatment histories as the people in our sample can engage in treatment and work with providers without having guardians manage their care or activities.

Under Missouri's own law, people who can receive and evaluate information, communicate their wants and needs, and manage their own care and financial resources—with or without help[51]—should not be under guardianship. During a training presented by its staff, the State acknowledged that "[w]e all have the right to make poor decisions." It warned that guardianships are not a "magic[]" solution to get a person to take medication or keep them in a residential setting. But in practice, in Missouri the determination of whether a person with a mental health disability needs a guardian is not always based on the person's ability to make and communicate decisions. It may instead be based on whether the person seeking the guardianship agrees with those decisions. For example, even though Lilian, described on pages 15-16 above, who the State labelled as "intelligent," provided a rational explanation for why she did not want to take her a particular medication—it made her feel drowsy and lethargic—a primary reason why the State sought guardianship is because it disagreed with that healthcare decision.

Guardianship is a blunt tool for addressing what is often a subtle challenge: due to the nature of mental health disabilities such as bipolar disorder and schizophrenia, any incapacity caused by the mental health disability is often temporary. Once the person is less symptomatic, their capacity returns, but the guardianship does not automatically end, and is often effectively permanent.

On paper, Missouri state law both provides a process to end guardianships[52] and requires guardians to submit an annual review stating, among other things, if the guardianship is still

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[50] Mo. Stat. Ann. § 475.075(11) ("On the other hand, if the court finds that the capacity of the respondent to receive and evaluate information or to communicate decisions is impaired to such an extent as to render the respondent incapable of managing some or all of the respondent's essential requirements for food, clothing, shelter, safety or other care so that serious physical injury, illness, or disease is likely to occur, or that the capacity of the respondent to receive and evaluate information or to communicate decisions is impaired to such an extent so as to render the respondent unable to manage some or all of the respondent's financial resources, the court shall appoint a guardian or limited guardian, a conservator or limited conservator, or both in combination.")

[51] Mo. Stat. Ann. § 475.075(13) ("Before appointing a guardian or conservator, the court shall consider whether the respondent's needs may be met without the necessity of the appointment of a guardian or conservator, or both, by a less restrictive alternative including, but not limited to . . . Supported decision-making agreements or the provision of protective or supportive services or arrangements provided by individuals or public or private services or agencies . . . .")

[52] Mo. Stat. Ann. § 475.083.

needed.[53] But public administrators and other stakeholders said that guardianships are terminated very infrequently,[54] and that these annual reviews are largely a formality.

Rather than guardianship, we found most of the people in our sample would benefit from other decision-making aid, such as Supported Decision-Making (SDM). In 2018, Missouri amended its guardianship statute to include a requirement that the court consider SDM agreements before appointing a guardian.[55] A SDM agreement is a tool that allows a person with a disability to appoint people they trust to give them advice and support them in making their own decisions.[56] Nearly all the staff at DMH contracted providers and psychiatric hospitals we asked about SDM were unfamiliar with it. This included those whose organizations actually file guardianship petitions or recommend guardianship to families. This confirmed what several stakeholders—two of whom are members of the group that developed the amendments—told us: the changes have been put into effect inconsistently across the state. The Missouri Association of Public Administrators (MAPA) stated in its report that "[public administrators] are too often assigned before alternatives have been exhausted."[57] A lack of familiarity and awareness of SDM and the perception that these alternatives are difficult to do or impractical seem to be some causes for why SDM has not been widely adopted. According to MAPA, public administrators "often do not have the bandwidth for limited guardianship or supported decision-making, even when it is preferable."[58]

In sum, with appropriate services, adults with mental health disabilities living in Missouri's nursing facilities generally can receive and evaluate information, communicate their decisions, and manage their own care. The imposition of guardianship despite this prevents them from doing so.

D. Adults with mental health disabilities living in nursing facilities could instead be appropriately served in integrated settings

We interviewed a representative sample of the State's nursing facility residents[59] with mental health disabilities and reviewed their medical records. Based on that sample, we conclude that

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[53] Mo. Rev. Stat. § 475.082.

[54] There is no meaningful centralized data available about the frequency of guardianships and/or restorations.

[55] *See* Mo. Rev. Stat. § 475.075(13)(4).

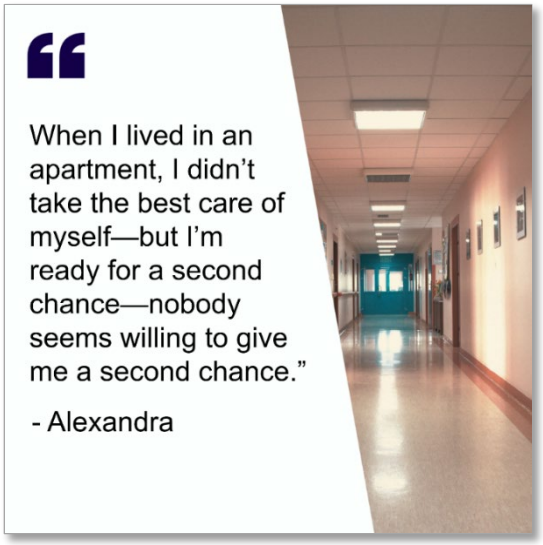
[56] *See Frequently Asked Questions*, National Resource Center for Supported Decision-Making, https://perma.cc/ME2W-59G7 (last visited Jan. 25, 2024). *See also* Supported Decision-Making, Missouri's Working Interdisciplinary Network of Guardianship Stakeholders, https://perma.cc/CR4T-FQYG (last visited Mar. 22, 2024).

[57] *See* Mo. Ass'n of Pub. Admins., *Missouri Public Guardianship Report*, Mo. Dep't of Mental Health 27 (Apr. 20, 2020), https://perma.cc/WDF4-8SYY.

[58] *See id.* at 15.

[59] We excluded residents with dementia, with Alzheimer's, and with nursing facility stays of 100 days or fewer, from this sample.

the vast majority of nursing facility residents with mental health disabilities are qualified and appropriate for community-based services, including Assertive Community Treatment, Permanent Supportive Housing, case management, peer support services, supported employment, and crisis services. Residents' medical records frequently cite impulse control and other behavior management challenges as justification for not offering community-based services, but these are issues that the services listed above can target. The people with mental health disabilities we met in Missouri's nursing facilities are similar to people who are successfully served in community-based settings in other states. Placement in nursing facilities is not necessary to provide personal care or help with daily living. Indeed, more than half of the people in our sample, and about three quarters of the people sampled in the High Volume Facilities, do not need any personal care or help with daily living. For people with mental health disabilities who also need physical help for daily activities like bathing and cleaning, that help is also available in the community through Medicaid. Thus, any physical care needs can likely be appropriately addressed in integrated community settings.



These findings are consistent with conclusions of both DMH staff and people working in nursing facilities. A State official acknowledged to us that there are people with mental health disabilities in nursing facilities who are not in the most integrated setting appropriate for them. Nursing facility administrators also acknowledged that at least some current residents did not need to live in their facilities.

Some stakeholders explained that many nursing facility residents with mental health disabilities are appropriate for community-based placements but are not given the opportunity because those alternative placements are not readily available. A public administrator who placed a person in a nursing facility said she would want to move that person to a Clustered Apartment (an individual apartment in a complex staffed by a DMH provider), if one was available. Other public administrators explained that they placed adults with mental health disabilities in nursing facilities not because they would get the treatment they needed in those institutions, but because there was no other option. One public administrator succinctly summarized: nursing facility placement is "a solution only because it's the only solution."

Moreover, people with mental health disabilities in nursing facilities are not routinely receiving mental health services beyond medication. Some High Volume Facilities have developed what they describe as mental health programs even though they do not include any mental health services. The programs are infantilizing, of low quality, not evidence-based, and lack structure. Nevertheless, discharge may be tied to successful completion of the "programs", which are designed to last at least four years. George, who has lived in nursing facilities for eight and a half years, said he has been in a program at his current nursing facility for three years: "I should've already completed it. They haven't told me how to pass. They don't inform us about much."

Public administrators, disability rights attorneys, an administrator of an ombudsman program, nursing facility residents, and loved ones confirmed that nursing facilities provide few, if any, mental health services beyond medication. “They don’t have any treatment for mental health,” said Natasha, whose brother lives in a High Volume Facility. “All they do is pass out meds.” Indeed, the extent of the mental health treatment offered at many nursing facilities is a psychiatrist visit once every one to four months for medication management. A deputy public administrator whose office has placed adults with mental health disabilities in nursing facilities said that visits from a psychiatrist every three months are “not enough to give ongoing treatment for mental illness.” A loved one of a resident captured the irony of Missouri’s unnecessary reliance on nursing facilities: “If she is locked up because of mental health issues, it only makes sense that she would be receiving mental health services, and she is not.” Without mental health services, any symptoms or challenges that led to a nursing facility placement are unlikely to be resolved,[60] so the practical effect is that people with mental health disabilities in nursing facilities are stuck indefinitely. This despite being appropriate for community-based services aimed at recovery.

Ruth was institutionalized in nursing facilities despite being qualified and appropriate for community-based services, but thrived once she was given community-based care. Ruth experienced night terrors and psychosis after an abusive relationship and was diagnosed with schizophrenia. Ruth said she was not offered community-based treatment, but if she had been: “[T]his never would have been as nasty as it was. It would have been a whole different story. It would have been completely different.” Instead, her parents filed a guardianship petition, and a public administrator was appointed. Rather than engaging Ruth in community-based treatment, the public administrator moved Ruth—who was in her 40s and had no physical care needs—into a nursing facility. Treatment there largely consisted of medication. She spent at least two and a half years institutionalized in nursing facilities. When she finally returned to the community after persistent self-advocacy, she got therapy and case management. These services enabled her to enroll in and graduate from college, connect with a church, and develop a network of friends. She now lives in an apartment with her cat, where she gets housing supports. She told us that living in a community-based setting “feels like I have me back.” Ruth is working on becoming a clinical counselor.

[60] Instead, nursing facilities can make recovery more difficult. One resident we met was 31-year-old Amber, who has been in nursing facilities for 11 years. She likes being outside, reading, and watching movies. She told us she wanted to enroll in a 12-step program for substance use disorder, but none was available at the facility she is in.

E. Adults with mental health disabilities living in nursing facilities do not oppose receiving services in integrated settings

1. People with mental health disabilities living in nursing facilities do not oppose returning to the community

Nearly all the people in our generalizable sample of people with mental health disabilities in nursing facilities said they wanted to return to the community. One individual told us if he'd known more, he would have fought his placement in a nursing facility "tooth and nail." The people we spoke to told us of their dreams of freedom and shared the simple moments of joy they'd experience if they could leave their nursing facilities. For example, Alice looks forward to being with her family at the beach in California, and having a picnic or barbeque. She added that: "I've always wanted to go to a fair." Dorothy, who is 35, would like to have a husband and children. She looks forward to having her own apartment and enjoying steaks, hot dogs, and fish. Elijah, a resident of nursing facility for 11 years, told DOJ: "Oh yeah, in a heartbeat. I'd fly through that door and be the happiest little ant in the world." We asked the nursing facility residents we visited: If a miracle happened where your life was now exactly as you wanted it, what would be different? The textbox on this page shows quotes from nursing facility residents with mental health disabilities responding to that question. They wished for nothing more than to engage in everyday integrated life activities, as envisioned by the ADA.

DOJ Asked: **If a miracle happened where your life was now exactly as you wanted it, what would be different?**

"I'd be living in my own place with a social worker that could help me out."
- Colton

"I'd be out on my own. I'd see a lot of my friends, travel to see my family."
- Nora

Ideal day: Drink coffee, laundry, clean, go into town, shop a little bit. "The normal things that people do."
- Elijah

"I'd have a good apartment that wasn't too many steps up and I'd have a therapy pet, like maybe a goldfish or something. That's it. I'm simple."
- Levi

Nursing facility residents with mental health disabilities wished for nothing more than to engage in everyday integrated life activities, as envisioned by the ADA.

These preferences are well known. Public administrators told us that most of their clients with mental health disabilities do not want to be in nursing facilities and that they were placed there because no other options were available. The operator of a large nursing facility in Kansas City was quoted in a newspaper as saying that residents there because of their mental health disability "don't want to be here," and that "[n]o one wants to have their loved one here."[61] An administrator at a High Volume Facility told DOJ: "everybody asks to leave, every day."

[61] Joe Robertson, *No place in system for severely mentally ill, so they're locked away in nursing homes*, The Kansas City Star (May 7, 2017), https://perma.cc/U22C-6AP3.

It is not surprising that people do not oppose transitioning to integrated settings, particularly given the conditions at some nursing facilities. For example, during our visits we noticed that a wing of one facility smelled of raw sewage from a broken toilet. Some had overwhelming smells of cigarette smoke and sewage. Staff and residents of some facilities described drug use by both staff and residents. There are resident-on-resident physical fights. The State knows about the concerning conditions at several High Volume Facilities, and multiple facilities serving this population have been flagged because of concerns about conditions and treatment.[62] Several residents interviewed by DOJ described their time in nursing facility as "hell." One told us: "a good chunk of me died in that" nursing facility.

A Missouri state official echoed this sentiment, saying, "If I had a mental illness and had to live in a locked unit in a nursing home, I wouldn't like that at all."

1. Public administrators agree that adults with mental health disabilities do not belong in nursing facilities

Public administrators we spoke with agree that people with mental health disabilities do not belong in nursing facilities. Public administrators rely on nursing facilities because there are few other options available in Missouri. As a public administrator who has clients with mental health disabilities living in nursing facilities told us, apart from institutionalized care "there's nothing else; there's [*sic*] very little options." Some public administrators told us they tried to find community-based placements for their clients but could not. Others said they would be open to trying community-based services if they were available. Others admitted that they were not familiar with the limited community-based options that do exist. But none of the public administrators we spoke to opposed increasing community-based alternatives to nursing facilities for the people they serve.

THE STATE COULD BUT DOES NOT USE EFFECTIVE COMMUNITY-BASED SERVICES INSTEAD OF NURSING FACILITIES AND GUARDIANSHIP

As described above, a common response in Missouri to people with mental health disabilities who have not successfully engaged in treatment is appointment of a guardian and placement in a nursing facility. However, there are community-based services that are specifically targeted at this population and are alternatives to this segregation. Missouri could, but has not, used these services to prevent nursing facilities admissions.

A. Before their placement in a nursing facility, many adults with mental health disabilities did not get intensive community-based mental health services

Abraham, who is in his late 20s, wants to work part time at a fast food restaurant and live in his own apartment or trailer around Kansas City. Instead, he lives in a locked nursing facility over 6 hours away. Before his institutionalization, Abraham was unhoused and had multiple hospitalizations, some of which were motivated by his need for shelter when it was cold.

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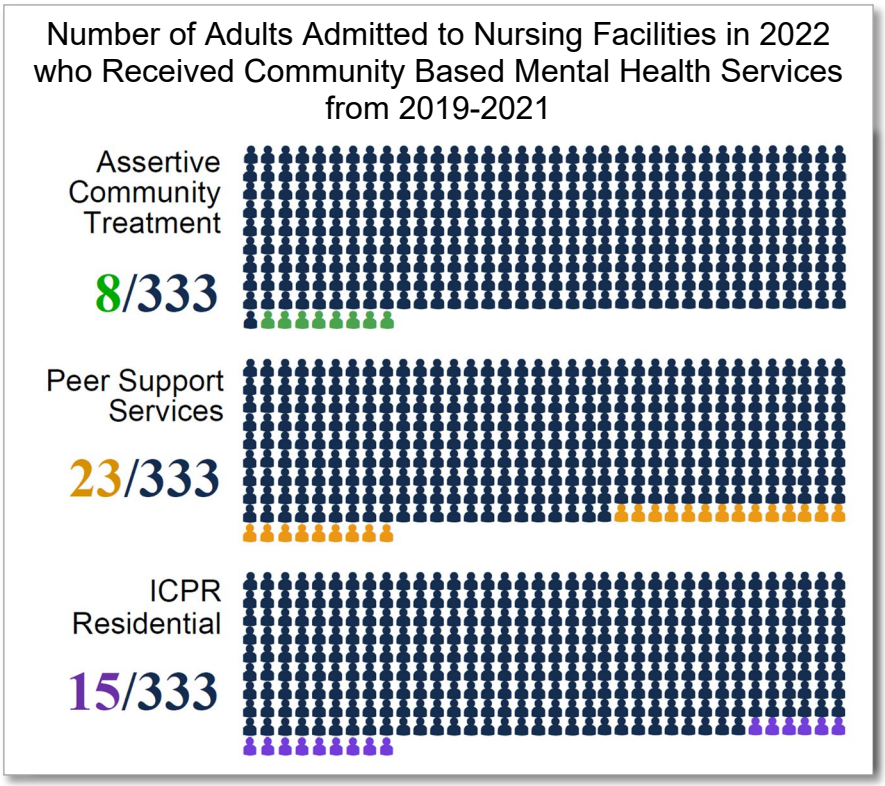
[62] Grace Kenyon, *Problems with oversight, staffing contribute to low quality ranking of Missouri nursing homes*, Columbia Missourian (Jan. 3, 2024), https://perma.cc/T3FW-DW8Z. One such facility, Levering Regional Health Center (a High Volume Facility), is closing down after it was terminated from participation in Medicare and Medicaid in May 2024 after persistent failures to bring its conditions into compliance with regulations. Most residents were moved to other nursing facilities.

Missouri did not provide Abraham with community-based services at the intensity necessary to avoid institutionalization. He got case management "off and on," medication, and therapy. But he did not report receiving intensive services such as Assertive Community Treatment—which Missouri does not require all CCBHOs to offer. Missouri's failure to provide Permanent Supportive Housing for adults with mental health disabilities also contributed to his institutionalization. One of DMH's regional providers tried to help Abraham, but there was no room in DMH's housing programs. Without access to needed services, Abraham's caseworker recommended guardianship, saying it would help him get Social Security benefits. A public administrator was appointed. His guardian has since placed him in three different nursing facilities.

A minority of the people in our sample reported receiving any community-based mental health services beyond medication and counseling before being institutionalized. We requested Medicaid billing data from the State that would show whether these reports were typical. Specifically, we looked at data for the 333 adults with mental health disabilities who entered nursing facilities between July and December 2022. The data showed mental health services each person got in the two and a half to three years before their nursing facility admissions. Most got a psychiatric evaluation. But as the infographic on this page illustrates, extremely few received ACT, housing services ("ICPR Residential"), or peer support, and none got Medicaid-funded supported employment. This data is consistent with reports we received from nursing facility residents and DMH contracted providers. Providers told us that it was rare for someone who was receiving services to then enter a nursing facility and residents told us they had not received services before entering the nursing facility. The State does not provide people at serious risk of entering nursing facilities with the needed services to divert them.



B. Missouri has not provided the Permanent Supportive Housing and Assertive Community Treatment necessary to prevent guardianship and unnecessary admission to nursing facilities, or support transitions from both

1. Assertive Community Treatment

Assertive Community Treatment (ACT) is an evidence-based model of care—which means it is proven to work. ACT provides comprehensive, community-based treatment to people with mental health disabilities.[63] ACT is delivered by an interdisciplinary team, whose members are trained in the areas of psychiatry, social work, nursing, substance abuse, and vocational rehabilitation. Services are highly individualized and designed to address the needs of people who have the most severe mental health disabilities and need the most wraparound care. This includes those who are high users of psychiatric hospitals and other institutions. ACT teams provide care directly to consumers in their homes and communities, as opposed to at offices or institutions. A DMH contracted provider described ACT as "essentially a hospital without walls."

A State official and several DMH-funded community-based mental health providers acknowledge that ACT is an effective way to prevent hospitalization and nursing facility placement.[64] This is because ACT teams see people regularly and can notice and respond quickly if their mental health declines. Missouri's ACT services have had positive outcomes, including allowing participants to keep a job, and improving quality of life.

Despite Missouri's recognition of the benefits of ACT, there are limited opportunities for people in Missouri to get ACT. One reason is that Missouri has limited ACT availability.[65] As the map on this page shows and DMH recognizes, some regions in the State have no ACT. [66] Even outside of these regions, ACT is an underused service. Several public administrators and staff of DMH contracted providers had not heard of ACT. After learning about the service, one

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[63] *Building Your Program: Assertive Community Treatment*, SAMHSA 5-6 (2008), https://perma.cc/B38V-V42H.

[64] The state official also said that ACT can be helpful in avoiding or getting someone out of a guardianship.

[65] *Missouri ACT Teams*, Mo. Dep't of Mental Health, https://perma.cc/AYQ3-2JGD (last updated Mar. 18, 2024).

[66] *Id.*

public administrator responded: “I would love this, how soon can we get this?” Compounding the issue, many providers incorrectly believe that ACT cannot be provided to people living in DMH’s specialized housing for adults with mental health disabilities. So they do not offer it to their clients even where it is available.

A State official told DOJ: “We need more ACT teams.” Most DMH contracted providers, public administrators, and directly impacted people we spoke to agreed. DMH could[67] but does not require its contracted regional providers to offer ACT. Around half of the adults in our sample were appropriate for and could benefit from ACT. Only eight of the 333 adults with mental health disabilities who entered a nursing facility in calendar year 2022 got ACT in the three years before their admission. Providing ACT could prevent many guardianships and nursing facility admissions for people with histories of frequent hospitalizations.

2. Permanent Supportive Housing

Permanent Supportive Housing (PSH) is an evidence-based service that offers voluntary, flexible supports to help people with mental health disabilities choose, get, and keep housing that is decent, safe, affordable, and integrated into the community.[68] The person with a mental health disability has a standard lease in their own name, for which they typically pay up to 30% of their income. People living in PSH may get mental health services from community-based providers. But their ability to stay in their home must not be conditioned on any special rules or participation in particular services, including compliance with medications or sobriety.[69] PSH units should be integrated. This means they are located throughout the community or in buildings in which most units are not reserved for people with disabilities, and residents have opportunities for interactions with the community. PSH is proven to reduce hospitalizations.

Missouri offers community-based housing for adults with mental health disabilities. But it does not offer enough to meet the need and prevent admission to—or return people to the community from—nursing facilities.[70] “Trying to find housing now is the ultimate crisis,” the director of a DMH contracted provider told us.

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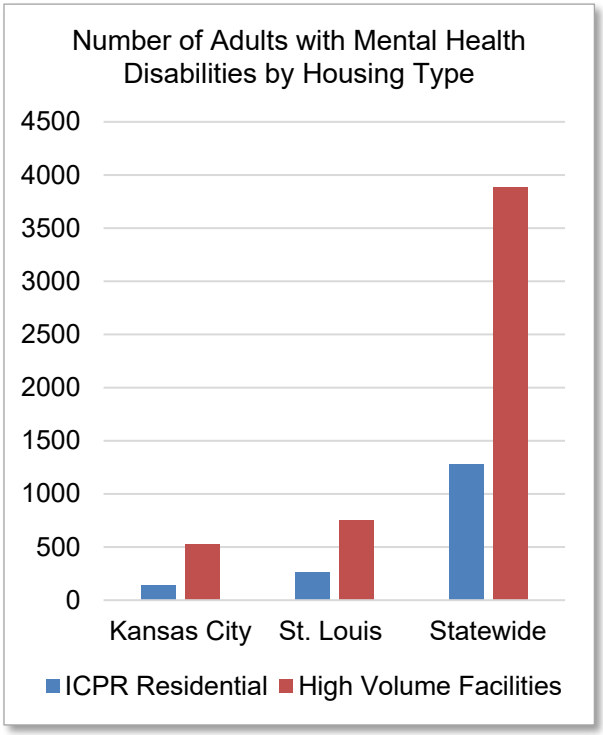
[67] *Certified Community Behavioral Health Center (CCHBC) Certification Criteria*, SAMHSA 33-34 (Mar. 2023), https://perma.cc/8W3Q-2GD8.

[68] *Permanent Supportive Housing*, SAMHSA, https://perma.cc/K5H3-BBY4 (last visited January 5, 2024).

[69] *Permanent Supportive Housing*: *Evaluating Your Program*, SAMHSA 27 (2010), https://perma.cc/YT4L-K5SA; *Permanent Supportive Housing: Training Frontline Staff*, SAMHSA 4 (2010), https://perma.cc/UT93-4X8M.

[70] More than a decade ago, the Missouri Institute of Mental Health (MIMH) conducted a statewide needs assessment and identified housing as one of the “major needs.” Later, regional workgroups that included DMH officials also found there were insufficient housing options for adults with mental illness in their areas. DMH is aware of the current need for additional housing, not just to transition nursing facility residents, but also to move residents from restrictive settings like RCFs. The 2020 DMH’s Least Restrictive Environment Review found that multiple people were unable to leave an RCF, even though a lesser restrictive option was more appropriate, due to a lack of ICPR Residential options.

Clustered Apartments are one of three types of housing offered as part of DMH's Intensive Community Psychiatric Rehabilitation Residential (ICPR Residential) services.[71] Clustered Apartments are individual apartments—with one resident per apartment—clustered together in one or more apartment complexes.[72] Either part time or full-time staff are available to assist residents.[73] Clustered Apartments scattered through different buildings can be used to provide PSH. One CCBHO reported that scattered apartments are preferable because buildings that are entirely Clustered Apartments are hard to manage and can be stigmatizing. Most of the Clustered Apartment sites we visited, however, were located in segregated buildings not offering PSH. For example, we visited Clustered Apartments where 100% of the units in a building were for adults with mental health disabilities. We also visited Clustered Apartments that offered only temporary rather than permanent housing and that made housing contingent on residents being enrolled in services with the DMH contracted provider. Missouri could expand existing PSH available in the State including through Clustered Apartments that offer PSH.



Only 17 of the 333 nursing facility residents with mental health disabilities who entered a nursing home in the calendar year 2022 received DMH's housing services in the three years before entering a nursing facility. This underscores that the State is resorting to institutionalization without offering less restrictive options. As the bar graph on this page illustrates, far more people are being housed in High Volume Facilities than in any of the ICPR Residential units.

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[71] *See Memorandum from Mo. Dep't of Mental Health to Community Psychiatric Rehabilitation (CPR) Providers on Intensive CPR for Adults in Residential Settings* (Nov. 13, 2020), https://perma.cc/S9EJ-8RM6. The two other housing types within the ICPR Residential program are Intensive Residential Treatment Setting (IRTS) and Psychiatric Individualized Supported Living (PISL). IRTS is a congregate living environment with five to 16 beds. Congregate means that residents live in proximity to each other and share common areas. At IRTS, full-time staff provide round-the-clock observation and oversight. PISL is a private home with two to four bedrooms. Each resident has their own room. Staff are available on a full-time basis. In addition to nursing facilities and ICPR settings, Missouri relies on Residential Care Facilities (RCFs) to serve adults with mental health disabilities. RCFs are congregate facilities that provide 24-hour care and oversight, including shelter, food, and medication administration. *See Level of Licensure for Long Term Care Facilities*, Mo. Dep't of Health & Senior Servs., https://perma.cc/ZKE8-3QFS (last visited Jan. 5, 2024). IRTS and RCFs are very similar. In fact, around 28% of IRTS sites are also licensed RCFs.

[72] *Id.*

[73] *Id.*

Almost all the people we reviewed are appropriate for integrated community housing, with mental health supports. For most of these people, PSH or a completely independent setting would be appropriate.

C. Other services that people with mental health disabilities need to avoid guardianship and institutionalization are available but limited

Many other mental health services are also limited in ways that prevent access by people who need them to avoid unnecessary nursing facility admission and guardianships. Some key services are not available in every region, resulting in gaps in coverage for people living in those areas. Others are available but are not being provided to people who demonstrate a need for more support to stay stable and independent.

1. Case Management – "Community Psychiatric Rehabilitation"

Community Psychiatric Rehabilitation (CPR or CPRP) refers both to the general package of services provided by DMH contracted providers to adults with mental health disabilities and to coordination of those services (i.e. case management). CPR services are "designed to maximize independent functioning and promote community adjustment and integration." In addition to case management, CPR includes assessment, treatment, community support services (help with developing and meeting goals, learning skills, and managing symptoms), and referrals to other services such as supported employment and peer support services. All of the adults in our sample were appropriate for and could benefit from CPR—or a more intensive service such as ACT or ICPR.

Missouri has also developed non-residential Intensive CPR services. Intensive CPR, or ICPR, is intended to prevent institutionalization or help people return to the community. In theory, it can be offered as a short term intensive service or on an ongoing basis as an alternative to ACT.[74] However, ICPR is not meeting the need for frequent contact or daily medication support. Instead, DMH contracted providers assume that those who need medication support belong in residential settings.

In practice, few people who need ICPR to avoid a nursing facility placement or to transition out actually get it. Only two people with mental health disabilities who were admitted to nursing facilities in calendar year 2022 had gotten non-residential ICPR in the three years before entering a nursing facility. Clearly, the service is not reaching this important target group.

2. Peer Support Services

Peer support services are a type of mental health care and support that is provided by individuals with lived experience of mental health and/or substance use recovery.[75] Peers provide a living example of understanding, respect, and empowerment; "by sharing their experiences, peers bring hope to people in recovery and promote a sense of belonging within

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[74] *Intensive CPR for Non Residential Adults*, Mo. Dep't of Mental Health (June 26, 2014), https://perma.cc/Z8SA-KZHP.

[75] *Peer Support Services*, Mo. Dep't of Mental Health, https://perma.cc/44AQ-RWT8 (last visited Jan. 5, 2024).

the community."[76] They "can effectively extend the reach of treatment beyond the clinical setting into the everyday environment of those seeking a successful, sustained recovery process."[77] Many providers we spoke to recognized the value of peer supports. Peer support services are critical to engaging people in care. This in turn is critical to reducing the "likelihood of a return to mental health symptoms" and avoiding institutionalization. One effective way peer supports can be delivered is through peer-run drop-in centers. Peer-run drop-in centers are community-based sites owned, administratively controlled, and managed by peers. The centers provide a welcoming environment and a wide range of activities, including support groups, recreational and social events, and linkages with support services.[78]

Missouri does not regularly use peer support to prevent the unnecessary institutionalization of people in nursing facilities. There are four peer-run drop-in centers in Missouri, in Springfield, St. Louis, Kansas City, and Cape Girardeau.[79] However, as DMH acknowledged in its most recent needs assessment the availability of peer supports "across the system of care is highly variable."[80] Peer support is one service our experts identified as necessary to support return to the community for a large majority of individuals in our sample. However, only 23 people of the 333 nursing facility residents with mental health disabilities admitted in calendar year 2022 got Medicaid-funded peer support services in the three years before admission.

3. Supported Employment

Supported employment services help people with mental health disabilities find and maintain meaningful, competitive, and paid employment.[81] It has, in the words of the State, "tremendous therapeutic value." Being engaged in a job can support stability in the community.[82] Individual Placement and Support (IPS) is an evidence-based supported employment model.[83] An essential value of IPS is that everyone with a mental health disability can work and everyone

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[76] *Id.*

[77] *Id.*

[78] *Building Your Program: Consumer-Operated Services*, SAMHSA 1, 55 (2011), https://perma.cc/LC5B-6AD8.

[79] *MO Consumer Operated Drop In Centers*, Mo. Dep't of Mental Health (Mar. 15, 2023), https://perma.cc/6CBB-7646.

[80] Jessica Bounds, *Certified Community Behavioral Health Organizations (CCBHO) Expansion in Missouri*, Mo. Dep't of Mental Health 31, https://perma.cc/C88T-G7ZU (last visited Jan. 5, 2024).

[81] *Division of Behavioral Health Employment Services*, Mo. Dep't of Mental Health, https://perma.cc/D8FL-2VL5 (last visited Jan. 5, 2024).

[82] Robert Drake et al., *Individual Placement And Support Services Boost Employment For People With Serious Mental Illnesses, But Funding Is Lacking*, Health Affairs 35:6 (June 2016), https://perma.cc/D23C-FR6Y.

[83] *The Evidence: Supported Employment*, SAMHSA 7 (2009), https://perma.cc/F2K9-LYXP.

with a mental health disability is eligible for the service right away.[84] Supported employment for adults with mental health disabilities is a Medicaid service in Missouri. DMH reports that half of IPS participants are employed within 90 days.

Many of the adults with mental health disabilities we spoke to—including those currently stuck in nursing facilities—said they wanted to work. When we asked Harris what he needed in the community to be successful, he told us he wanted a job. Christopher told us his wish was to be in his own apartment and trying to get a job. Eddie said he wants a job in landscaping. Almost half of all the adults in our sample—including Harris, Christopher, and Eddie—are appropriate for supported employment. There are 33 IPS sites across Missouri, but areas of the State remain unserved.[85] None of the adults with mental health disabilities who entered a nursing facility in calendar year 2022 got Medicaid-funded supported employment in the three years before their admission.

4. Mobile Crisis Response

Mobile crisis teams provide community-based interventions to people experiencing mental health crises. The goal is to provide rapid response, assessment, and resolution wherever the person is experiencing the crisis.[86] Mobile crisis services are "effective at diverting people in crisis from psychiatric hospitalization, effective at linking suicidal individuals discharged from the emergency department to services, and better than hospitals at linking people in crisis to outpatient services."[87] For this reason, they are an essential part of any mental health system.

The mobile crisis response system in Missouri is in flux, as the State sets up the nationwide 988 suicide and crisis line. While the State has established statewide coverage for mobile crisis response when needed, the State does not ensure that central elements of mobile crisis are consistently provided across the State. This includes staffing for mobile crisis teams, and connection to lasting services after the crisis intervention. [88] To prevent people from entering nursing facilities after a crisis and to support people returning from a nursing facility who may experience a mental health crisis in the future, mobile crisis will be key.

The impact of the service in diverting people and connecting them to lasting support is also not clear currently. This is because the State does not track whether people who experience mental health crises are current users of other mental health services or are successfully connected to services after their crisis. In a system where unresolved mental health crises can start a person

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[84] *Building Your Program: Supported Employment*, SAMHSA 3-4 (2009), https://perma.cc/J5XL-WLSR.

[85] *Individual Placement & Supports Program Sites Map*, Mo. Dep't of Mental Health (Oct. 16, 2023), https://perma.cc/43JZ-2W9V

[86] *National Guidelines for Behavioral Health Crisis Care Best Practice Toolkit*, SAMHSA 18-19 (2020), https://perma.cc/3KJN-TP7T.

[87] *Id.* at 19.

[88] National standards call for mobile crisis coverage to be team based, make use of peer support specialists, and provide a truly mobile response all day every day. *Id.* at 18, 21. Connecting people to lasting services is, according to SAMHSA, an "essential element" of crisis response. *Id.* at 21.

down the pathway to guardianship and a nursing facility, monitoring to ensure that people who experience crises are connected to lasting mental health services is key.

5. Crisis Stabilization Services

Crisis stabilization services are provided in community settings as an alternative to emergency room and hospital admissions to help stabilize a person in crisis and connect them to lasting care.[89] National guidelines describe crisis centers as safe settings in the community that accept all referrals and walk-in visits from people in crisis regardless of acuity.[90] A multidisciplinary team of peers and clinical staff support these individuals to resolve crises in 24 hours or less and coordinate connections to lasting care.[91] Peer-operated respite programs, where peers with lived experiences provide crisis services in a restful, sanctuary environment are another valuable crisis service that can enable people to stabilize without entering an institutional setting.[92]

Missouri's CCBHOs offer crisis stabilization services at community-based sites called Behavioral Health Crisis Centers across the state. As of May 2024, there are 18 centers in the state,[93] with plans to develop five more centers.[94] When people who are currently in or at risk of nursing facility placement are in the community and seeking to resolve a crisis short of an institutional admission to a psychiatric hospital, crisis stabilization services are a critical tool. But in Missouri, the crisis stabilization system is currently inconsistent: not all the centers are open 24/7[95] and beds are often at capacity. Areas of the State also remain unserved.[96]

6. Outreach and Engagement Initiatives

DMH has some outreach and engagement initiatives aimed at working with people with mental health disabilities who are high cost, frequent hospital users. Disease Management 3700 is a project to identify people with mental health disabilities who are high-cost users of Medicaid services and assign DMH contracted providers to conduct intensive outreach to them to engage frequent users in services. It began in 2010 and showed "improvements in the health status of

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[89] *Id.* at 22-23

[90] *Id.* at 12, 22-23.

[91] *Id.* at 22-23

[92] *Id.* at 25

[93] Eight of the centers are structured as urgent care units and one is specialized in substance use. There are several peer-operated respite programs for substance use, but none for mental health disabilities.

[94] Mo. Behavioral Health Council & Mo. Dep't of Mental Health, *Behavioral Health Crisis Centers*, Mo. Behavioral Health Council, https://perma.cc/J7AQ-K9D9 (last visited Jan. 5, 2024); *Behavioral Health Crisis Centers*, Mo. Behavioral Health Council (Feb. 2024), https://perma.cc/S8VW-QLAS

[95] *Id.*

[96] Mo. Behavioral Health Council & Mo. Dep't of Mental Health, *Behavioral Health Crisis Centers*, Mo. Behavioral Health Council, https://perma.cc/J7AQ-K9D9 (last visited Jan. 5, 2024) (map of BHCCs).

the individuals who were engaged in services and significant reductions in the cost to Medicaid for their care."[97] There is also funding available for providers to hire staff to work on Emergency Room Enhancement (ERE). ERE trains hospital staff to refer people with mental health disabilities who are frequent users of emergency room (ER) services to ERE outreach workers, who connect those people to community-based mental health services.[98]

The State reports a reduction in hospitalizations, ER visits, homelessness, and unemployment for people who are connected to community-based services through ERE.[99] Community Behavioral Health Liaisons perform a similar function for people who interact with law enforcement and the criminal justice system.[100] In sum, the State's own data show that its outreach and engagement efforts, when they occur, successfully help Missourians with mental health disabilities access community-based services and avoid institutionalization. However, the number of people currently in restrictive guardianships and nursing facilities after repeated emergency room or hospital stays shows that these outreach and engagement initiatives are not actually reaching many in the population they are intended to serve.

7. Supported Decision-Making

As discussed on pages 15 and 20, Supported Decision-Making (SDM) could serve as an alternative to guardianship for many adults with mental health disabilities in Missouri. DMH worked with a coalition to create resources for people using alternatives to guardianship, which are available online.[101] But SDM is not being offered or implemented widely.

SDM is consistent with the services described above. For example, case managers can assist clients with identifying areas in their life where they need assistance, what kind of assistance they need, and who could provide it. Case managers can also provide information and assistance with filling out forms such as health information releases. In addition, support and assistance with making decisions related to housing, employment, and healthcare is a key component of ACT, PSH, peer support services, supported employment, and case management. Thus, each of these services could be used to support a person using SDM in place of a traditional guardianship.

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[97] *DM 3700 Clients Enrolled in CMHC Healthcare Homes*, Mo. Dep't of Mental Health 2 (Feb. 21, 2014), https://perma.cc/Q93H-24U5.

[98] *FY 2023 ERE Infographic*, Mo. Dep't of Mental Health 2, https://perma.cc/D44F-8JXJ (last visited Jan. 5, 2024).

[99] *Id.*

[100] *CBHL Staffing and Job Expectations*, Mo. Dep't of Mental Health (Jan. 2023), https://perma.cc/HL2Q-FWVS.

[101] Alternatives to Guardianship Project, *Materials*, MO Guardianship (Sept. 2013), https://perma.cc/5ZNQ-RQHF. The Alternatives to Guardianship Project is collaboration between the UMKC-Institute for Human Development, UCEDD, the Missouri Developmental Disabilities Council, Missouri Protection & Advocacy Services, and the Missouri Department of Mental Health. *See id*.

MISSOURI HAS FAILED TO DIVERT AND TRANSITION ADULTS WITH MENTAL HEALTH DISABILITIES FROM NURSING FACILITIES

Missouri has made deliberate policy choices that result in unnecessary institutionalization of people with mental health disabilities in nursing facilities.[102]

A. Missouri's nursing facility eligibility criteria and reimbursement systems enable and encourage the long-term use of nursing facilities for people with mental health disabilities

Missouri has set up a system that allows people with mental health disabilities who do not have physical health needs to be considered eligible for nursing facility admission. This results in unnecessary segregated placements. In Missouri, a person qualifies for a nursing facility if they "exhibit physical impairment, which may be complicated by mental impairment or mental impairment which may be complicated by physical impairment, severe enough to require…skilled nursing care."[103] When assessing whether a person meets this standard, Missouri uses a point system. Anyone who reaches 18 points is eligible to go to a nursing facility,[104] and it is relatively easy to accumulate the necessary 18 points without any, or with minimal, physical health care needs. Missouri assigns nine points if the person has an "unstable mental condition" monitored by a professional at least monthly and the person is exhibiting behavior symptoms or if the person is exhibiting "psychiatric conditions." Nine more points are assigned for "displaying consistent unsafe or poor decision-making." Three more points are assigned if the person needs some help with medication, including setting it up or supervision. This results in many people with mental health disabilities being found eligible without physical health needs.

The recent roll out of this 18-point system was intended to increase nursing facility eligibility for adults with mental health disabilities. The system was designed based on the faulty assumption that expanding nursing facility eligibility would increase this group's access to needed community-based services. Eligibility for some kinds of community-based services are tied to institutional eligibility.[105] But the community-based mental health services offered at DMH contracted providers are available to all Medicaid-enrolled individuals who meet the diagnostic

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[102] Missouri reduced the number of adults with mental health disabilities institutionalized long-term in its state psychiatric hospitals. A former state official and CMHC leader said the State did not create sufficient community-based housing options for people leaving hospitals. So many adults with mental health disabilities still went to nursing facilities. In response, nursing facilities rebranded and marketed themselves to guardians as providers of secure housing and other basic services.

[103] Mo. Code Regs. Ann. tit. 19, § 30-81.030(5)(E)(4)(C).

[104] *Id.* 30-81.030(5)(E)(5)(C).

[105] Go Long Consulting, *Technical Assistance Report to The State of Missouri Department of Health and Senior Services on the Nursing Facility (NF) Level of Care (LOC) Transformation*, Mo. Dep't of Health and Human Servs. (Dec. 2018), https://perma.cc/XG6P-GXB5; *DHSS Home & Community Based Services Waiver Summary*, Mo. Dep't of Social Servs. (Jan. 5, 2023), https://perma.cc/B6PU-8CCY (waivers require people to meet nursing facility level of care).

criteria, without regard to whether they qualify for nursing facility admission.[106] Making it easier to qualify for a nursing facility doesn't make those mental health services more accessible to people with mental health disabilities. But it does encourage needless admissions to a less integrated setting.

Missouri is aware of and encourages the concentration of people with mental health disabilities in the High Volume Facilities. The State recently changed its payment methodology.[107] It now adds an extra $5 per resident/per day if 40% or more of a facility's Medicaid residents have schizophrenia or bipolar disorder. This encourages the concentration of people with mental health disabilities.[108]

For State Fiscal Year 2023, excluding the extra $5, the daily rate for nursing facilities ranged from $156.52 to $382 per person. Assuming each of the 3,289 people with mental health disabilities who do not have a co-occurring diagnosis of Alzheimer's and dementia spent a full year in a nursing facility billing the median daily rate, Missouri Medicaid spent $222.8 million on those nursing facility stays in Fiscal Year 2023. This does not account for the extra $5/day.

B. Missouri's system does not divert people with mental health disabilities from nursing facilities

Missouri is required to have a Preadmission Screening and Resident Review ("PASRR") system.[109] PASRR requires a screening whenever a person seeks admission to a Medicaid-certified nursing facility to identify if they have a "serious mental illness" and if so, whether they need a nursing facility level of service.[110] It is an important process "to help ensure that individuals are not inappropriately placed in nursing homes for long term care."[111] Congress mandated PASRR "specifically to end the practice of inappropriately institutionalizing individuals with mental illness…in nursing homes."[112]

Applicants who may have a "serious mental illness" must be evaluated to confirm the diagnosis and decide the answer to three questions. These are: (1) Can the individual's needs instead be met in a community setting? (2) If not, is a nursing facility appropriate? (3) If a nursing facility is

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[106] *Mental Illness – Adults and Children*, Mo. Community Options & Resources, https://perma.cc/43ZG-FKQB (last visited Jan. 5, 2024) (mental health services available to anyone Medicaid-eligible)

[107] *Missouri Medicaid Nursing Facility Reimbursement Methodology Summary for Fiscal Year 2023*, Mo. Dep't of Health & Senior Servs., https://perma.cc/Z2G8-PWEA (last visited Jan. 5, 2024).

[108] *Id.*

[109] 42 U.S.C. § 1396r(e)(7). PASRR requirements apply to people with serious mental illness and to people with intellectual disabilities. For purposes of this investigation, we limit our discussion only to people with mental illness.

[110] 42 C.F.R. §§ 483.128(a), 483.112(a).

[111] Centers for Medicare & Medicaid Services, *Preadmission Screening and Resident Review*, Medicaid.gov, https://perma.cc/37WQ-RJW9 (last visited Jan. 5., 2024).

[112] *Joseph S. v. Hogan*, 561 F. Supp. 2d 280, 285 (E.D.N.Y. 2008).

appropriate, are Specialized Services needed?[113] These determinations are separate and apart from whether a person meets the eligibility criteria described on page 34 above.[114]

Despite labeling PASRR as a tool for diversion,[115] Missouri does not in fact use it as one. Between State fiscal years 2019 and 2023, on average less than 2% of nursing facility residents each year were deemed inappropriate for a nursing facility after a Level II evaluation. In Missouri if a person is found to meet the Level of Care for a nursing facility, the PASRR Level II evaluation does not divert the individual from a nursing facility, unless the person is assessed to require inpatient hospitalization.

Missouri also does not use data about the number of PASRR evaluations or their outcomes to measure whether the PASRR system is serving its diversionary goal. Nor does Missouri use data from PASRR Level II evaluations to measure demand for community-based services that could prevent nursing facility admissions. Missouri furthermore does not use data to monitor whether people in nursing facilities are appropriate for discharge to a more integrated setting.

In sum, Missouri uses PASRR in precisely the problematic way described in a 2015 report by the federally-funded PASRR Technical Assistance Center: as "merely an administrative step in the nursing home admission process—a series of boxes to be checked."[116]

C. Missouri lacks other effective processes to support diversion and transition from nursing facilities

Missouri does not have a plan that shows how it will work to divert and transition people with disabilities from institutions, in compliance with the ADA. Other than—in theory but not in practice—PASRR, the State has no processes, services, or initiatives that are specifically intended to help divert people with mental health disabilities, or transition them from nursing facilities.[117] Without them, the current segregation of people with mental health disabilities continues. Existing processes, services, and initiatives that divert and transition people from institutions are not effectively targeting this population:

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[113] 42 C.F.R. §§ 483.130(l), (m). This is called a Level II evaluation. *Id.* at § 483.128(a).

[114] *See id.* § 483.132. Thus, one potential outcome of the PASRR Level II determination is that the person cannot be admitted to a nursing facility because they do "not require the level of services provided by a" nursing facility. *Id.* § 483.130(m)(2).

[115] *PASRR Level II Evaluations*, Mo. Dep't of Mental Health, https://perma.cc/5YXZ-EUJQ (last visited Jan. 5, 2024).

[116] *2015 PASRR National Report: A Review of Preadmission Screening and Resident Review (PASRR) Programs*, PASRR Technical Assistance Center 7 (Dec. 2015), https://perma.cc/XVB7-48QH.

[117] We asked the State if it had any such processes, services, or initiatives. The State responded by identifying most of the community-based services described on pages 26-33 of this report. We agree that the existence of community-based services is necessary for compliance with the ADA. But, without targeted work to ensure that people with mental health disabilities in fact get those services and are diverted and transitioned from nursing facilities, the existence of those services is not sufficient.

- **Additional Assessments**: When people are hospitalized for mental health reasons, Missouri has requirements for additional assessments of people with extended stays to determine whether continued hospitalization is appropriate. Missouri does not have any similar requirements for people with mental health disabilities in nursing facilities, even though people with mental health disabilities should be expected to improve with appropriate care.[118]

- **Money Follows the Person:** Missouri put in place the Money Follows the Person (MFP) program to help people move out of nursing facilities and transition to community living. However, the program targeted older people and people with physical disabilities. As of August 2021, only 1.9 percent (40 out of 2,161) of the people who transitioned from a nursing facility through MFP since approximately October 2007 were identified as having a mental illness.

- **Least Restrictive Environment Reviews:** DMH conducts reviews of whether people in some residential facilities are in the least restrictive environment. But it does not conduct the reviews in nursing facilities.[119]

- **Mental Health Healthcare Homes:** Mental Health Healthcare Homes are programs (not physical spaces) that are "designed to integrate care for chronic health conditions into the CMHC setting" by also monitoring each person's physical health conditions and intervening when appropriate.[120] The State identified healthcare homes as a program that diverts people from nursing facility placement. Because most people with mental health disabilities are not entering nursing facilities due to physical health challenges, healthcare homes are not a program that can reasonably be expected to divert them from nursing facility placement.

In addition to these examples, Missouri has failed to divert and transition adults with mental health disabilities from guardianships that place them at higher risk of institutionalization in nursing facilities. Guardians can and have prevented people with mental health disabilities from

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[118] Some people who get a Level II PASRR evaluation may be recommended for a second evaluation after 180 days. However, this second evaluation is much like the first—an exercise in form completion and not a meaningful opportunity to identify people who could be appropriately served in a community setting.

[119] While Least Restrictive Reviews are a positive activity, the State does not actually help with transitioning everyone the State identifies as appropriate for a more integrated setting to those settings. For example, DMH found that 43-year-old Roy, who was living in an RCF at the time, was appropriate to "live on his own with continued support from [DMH contracted provider] and his psychiatrist for symptom and medication support." Five months later his public administrator placed him in a nursing facility. Despite Missouri's failure to divert and transition him, Roy still dreams of living in the community and wants to start a business. He said his wish is to "gain my life back from what's been taken from me…That's the American Dream that's been taken from me."

[120] *Community Mental Health Center (CMHC) Healthcare Homes*, Mo. Dep't of Mental Health, https://perma.cc/9EGA-VZNR (last visited Jan. 5, 2024). For 2021, the most recent year for which the State published an annual report, the State reported improvements in various markers of physical health and some achievement of program goals.*MO CMHC Healthcare Home Annual Report 2021*, Mo. Dep't of Mental Health https://perma.cc/HY2U-EP5V.

discharging from nursing facilities and accessing community-based services by refusing to consent to alternative services. Sometimes these actions conflict with the recommendations of nursing facilities or providers themselves.[121] During the 2020 least restrictive environment reviews conducted at RCFs, DMH concluded that for several people, the guardian was a barrier to integration. Despite the State's awareness of how guardianship can perpetuate unnecessary restriction and isolation, Missouri has failed to offer guardians education regularly and systemically on its community-based mental health services or to assist with or promote guardianship terminations. Missouri does not take steps to reevaluate the need for the guardianships it has filed or to assist adults with mental health disabilities in ending unnecessary guardianships.

DMH FAILS TO EXERCISE MEANINGFUL OVERSIGHT OF THE BEHAVIORAL HEALTH SYSTEM TO PREVENT UNNECESSARY NURSING FACILITY PLACEMENT

DMH's approach to regulating the mental health system contributes to the dynamics described in this Report. Some of this can be traced to the diffuse responsibility among state agencies for people with mental health disabilities in nursing facilities. In short: DMH is the agency responsible for "maintain[ing] and enhance[ing] intellectual, interpersonal, and functional skills of individuals" with metal health disabilities.[122] DHSS handles licensing and certification, and investigations of abuse and neglect. Medicaid pays the bills. This allows each agency to assume that the other two agencies are taking steps to ensure that the complete service delivery system runs efficiently, effectively, and in accordance with the ADA. But when it comes to intensive services for people with mental health disabilities, none of the agencies are doing so and none of the agencies are collaborating with the others to ensure there are no gaps.

Key State officials and DMH contracted providers are not focusing attention or resources on the thousands of adults with mental health disabilities in nursing facilities. The invisibility of this institutionalized people means that the State does not work to address it.[123] For example, the State does not use PASRR to identify people entering institutions without connection to appropriate mental health services, geographic gaps in mental health service availability, or unmet demand for additional services. We did not identify any evidence that the State uses the data gathered by PASRR to monitor performance of the system for serving people with mental health disabilities.

The State also does not ensure that its staff and contracted providers engage in necessary service coordination and planning to support informed choice and transitions. It does not require that providers connect with people with mental health disabilities to assist in transitions from

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[121] According to the manual for the mental health program referenced on page 21 above that is offered at many of the High Volume Facilities, the program "is designed to show your guardian how much you have grown." A staff member in charge of discharge planning at a High Volume Facility acknowledged that some guardians will refuse a more integrated setting even when the facility believes it is appropriate.

[122] Mo. Rev. Stat. § 630.020(2).

[123] The Director of DMH's Division of Behavioral Health agreed that the mental health service system bears responsibility for diverting and transitioning people with mental health disabilities away from nursing facilities. But this viewpoint was drowned out by her colleagues who consistently said they were unaware of or not responsible for (or both) the population of adults with mental health disabilities currently in nursing facilities.

nursing facilities. When DHSS APS workers encounter someone who is not being appropriately served by a DMH provider, there is no mechanism for DHSS to engage with DMH to hold that provider accountable. There is also no evidence that the needs of this cohort are considered when setting service delivery targets or assessing whether the mental health service system is meeting the needs of adults with mental health disabilities. In sum, because the State has not focused on the thousands of adults with mental health disabilities stuck in nursing facilities unnecessarily, it is not managing its system to divert them from these settings or to help transition them out.

IT IS A REASONABLE MODIFICATION TO SERVE ADULTS WITH MENTAL HEALTH DISABILITIES IN THE COMMUNITY

The evidence described above shows that people with mental health disabilities in Missouri are not being served in the most integrated setting appropriate, violating the ADA's prohibition against unnecessary isolation.[124] The State must make reasonable modifications to its system to avoid this discrimination, unless doing so is a fundamental alteration.[125] Here, the State must provide critical community-based services to people who would otherwise be unnecessarily institutionalized in nursing facilities. Missouri must also provide alternatives to guardianship. And the State must carry out effective diversion and transition planning to reduce unnecessary segregation. The changes that are needed are not fundamental alterations.

Providing community-based services including ACT, Permanent Supportive Housing, peer support services, supported employment, crisis services, and Supported Decision-Making to people who would otherwise be in nursing facilities is a reasonable modification. These services have already been identified by the State as effective and are already available to some in Missouri. Providing these same services to people who need them to transition from and avoid nursing facilities is reasonable.

Most of the community-based mental health services in Missouri are provided through CCBHOs, which are intended to expand and improve "the availability, accessibility, and quality" of services.[126] The State recognized that shifting to a CCBHO model "would require significant expansion of the scope of services and practices available in some service areas."[127]

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[124] 42 U.S.C. § 12132; 28 C.F.R. § 35.130(d).

[125] 28 C.F.R. § 35.130(b)(7).

[126] *Narrative Section of Missouri's Application to Participate in the Demonstration*, Mo. Dep't of Mental Health 18-19, https://perma.cc/2XW7-42Z9 (last visited Jan. 5, 2024).

[127] *Id.* at 19-20.

But that expansion was consistent with the State's priorities of expanding community-based service and de-institutionalization. The State also recognized the importance of tracking who actually gets services and measuring program effectiveness based on whether the people who need care actually get it.[128] It is reasonable, and not a fundamental alteration to hold Missouri to its own goals and commitments.[129]

The fact that some of these changes might result in short-term increases in spending does not render them unreasonable.[130] Missouri has recognized that serving people in community settings instead of nursing facilities is likely to result in cost savings.[131] In the long term, the costs are largely comparable. For State Fiscal Year 2023 the daily rate for nursing facilities ranged from $156.52 to $382 per person, without accounting for the potential $5/day mental health premium payment. The daily rate for community-based mental health services ranges from $204.80 to $304.91. It is billed only on days when a person gets services. By definition, every day in a nursing facility is a billable day for every person. By contrast, not all people will get mental health services every day. One State employee acknowledged to us that nursing facilities are the "least cost-effective option" for supporting someone.

As described on pages 36-38 above, Missouri already has diversion and transition processes, services, and initiatives that target people in or at risk of entering other institutions. It is inherently reasonable to make sure those processes, services, and initiatives are effective and target people with mental health disabilities in nursing facilities too. Similarly, it is reasonable, and not a fundamental alteration, for Missouri to use its PASRR program in a manner that effectively diverts people from nursing facility admissions when they could live in a more integrated setting.

Missouri must also address its inappropriate reliance on guardianship to serve adults with mental health disabilities. Missouri has an obligation under the ADA to avoid unnecessary institutionalization of adults with mental health disabilities—which is facilitated by Missouri's use

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[128] *Id.* at 24.

[129] *Henrietta D. v. Bloomberg*, 331 F.3d 261, 280-81 (2d Cir. 2003) (upholding as a reasonable modification an order requiring agency to "perform its statutory mandate"); *Townsend*, 328 F.3d at 519 (holding remedy was a reasonable modification, finding it consistent with the State's "explicit policy preferences for home- and community-based care"); *Haddad v. Arnold*, 784 F. Supp. 2d 1284; 1304-07 (M.D. Fla. 2010) (holding the provision of a service that the State chose to include in its own service system to additional individuals is not a fundamental alteration); *Messier v. Southbury Training School*, 562 F. Supp. 2d 294, 344-45 (D. Conn. 2008) (same).

[130] *Pa. Prot. & Advocacy, Inc. v. Pa. Dep't of Pub. Welfare*, 402 F.3d 374, 380 (3d Cir. 2005) ("budgetary constraints alone are insufficient to establish a fundamental alteration defense"); *see also Fisher v. Okla. Health Care Auth.*, 335 F.3d 1175, 1183 (10th Cir. 2003) ("If every alteration in a program or service that required the outlay of funds were tantamount to a fundamental alteration, the ADA's integration mandate would be hollow indeed.").

[131] *Rapid Response Review – Assessment of Missouri Medicaid Program Final Report*, Mo. Dep't of Social Servs. 43 (Feb. 11, 2019), https://perma.cc/W4X5-B6V6 ("Opportunities to improve quality and control costs of LTSS are primarily to be realized from increasing the proportion of LTSS recipients that receive services at home or in the community rather than in more costly institutional settings, and improving care planning and care management of members regardless of their setting of care.").

of guardianship. Missouri established Supported Decision-Making as an alternative to guardianship under the law. In doing so, Missouri itself identified a reasonable modification that could, in combination with community-based services, prevent unnecessary segregation for people who need some help managing their affairs.[132]

In sum, Missouri could serve adults in the most integrated setting appropriate to their needs and comply with Title II of the ADA by reasonably modifying its service system. This must necessarily include remedies aimed at eliminating the State's reliance on guardianship. Remedial measures should include:

- **Ensuring that community-based services are available and are provided to people who need them to prevent unnecessary guardianships and nursing facility placement.** Services the State should ensure are available and accessible include Assertive Community Treatment, peer support, supported employment, Intensive Community Psychiatric Rehabilitation (ICPR Non-Residential), mobile crisis response, and crisis stabilization services. The State should consider input from adults with lived experience in expanding its services.

- **Ensuring that integrated housing is accessible and available in sufficient quantities to prevent unnecessary institutionalization.** This would include expanding availability of Permanent Supportive Housing including Clustered Apartments that offer PSH.

- **Ensuring that transition services from nursing facilities effectively assist nursing facility residents with mental health disabilities who do not oppose living in a more integrated setting to make choices about living settings and transition out of nursing facilities.** This will include doing regular in-reach in nursing facilities to identify adults with mental health disabilities who wish to transition to, or are interested in learning more about, integrated housing with supports; providing individualized education on available community-based services and supports (including through peer support) to adults with mental health disabilities and their guardians; engaging in comprehensive transition planning; and ensuring that the people have access to services they need to stay in community-based settings post-transition. The State should ensure that the rights of people under guardianship to speak to people of their choosing are not violated through this process, and that people under guardianship can get in-reach.

- **Ensuring effective diversion from nursing facilities.** This would include identifying people when admission to nursing facilities is sought, identifying their needs and the most integrated setting appropriate to those needs, and engaging in assertive efforts to direct them to those settings. This can be done using the federally mandated PASRR process or other processes.

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[132] *See* 28 C.F.R. § 35.130(b)(7)(i); Mo. Rev. Stat. §475.075(13)(4) (2022) ("Before appointing a guardian or conservator, the court shall consider whether the respondent's needs may be met without the necessity of the appointment of a guardian or conservator, or both, by a less restrictive alternative including, but not limited to . . . Supported decision-making agreements or the provision of protective or supportive services or arrangements provided by individuals or public or private services or agencies.").

- **Ensuring appropriate diversion and transition from unnecessary guardianships for adults with mental health disabilities.** This should include expanding Supported Decision-Making; training State employees, psychiatric hospitals, and service providers on the use of guardianships and alternatives to guardianship; revising State policies on when to petition for guardianship; regularly reviewing the capacity of people under guardianships who get services from the State and seeking to terminate unnecessary guardianships; and ensuring meaningful oversight over public administrators.

CONCLUSION

We conclude that there is reasonable cause to believe the State fails to provide services to adults with mental health disabilities in the most integrated setting appropriate, in violation of the ADA.[133] Because of deficiencies in its community-based service array and the manner in which the State administers its adult mental health system, the State relies on segregated settings to serve adults with mental health disabilities who could be served in their homes and communities.

We look forward to working cooperatively with the State to reach a resolution of our findings. We are required to advise you that if we cannot reach a resolution, the United States may take appropriate action, including bringing a lawsuit, to ensure the State's compliance with the ADA. Please also note that this Report is a public document. It will be posted on the Civil Rights Division's website.

[133] *See* 42 U.S.C. § 12132; 28 C.F.R. § 35.130(d).