INVESTIGATION OF GLENWOOD AND WOODWARD RESOURCE CENTERS

United States Department of Justice
Civil Rights Division

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I. SUMMARY OF FINDINGS

After an extensive investigation, the United States Department of Justice (DOJ) concludes there is reasonable cause to believe that the State of Iowa violates Title II of the Americans with Disabilities Act (ADA), 42 U.S.C. § 12132, by failing to provide services to people with intellectual/developmental disabilities (IDD) in the most integrated setting appropriate to their needs. Consistent with the statutory requirements of the Civil Rights of Institutionalized Persons Act (CRIPA), 42 U.S.C. § 1997b, and Title II regulations, 28 C.F.R. § 35.172, we provide this Report to notify Iowa of DOJ's conclusions with respect to these violations, the facts supporting those conclusions, and the minimum remedial measures necessary to address the identified deficiencies.

Iowa's system of care for people with IDD is heavily biased toward institutions. The system drives people with IDD to institutions for multiple reasons, including inadequate community alternatives to institutions for behavioral, crisis, and physical health supports. We focus in this Report on Iowa's two large residential institutions for people with IDD: Glenwood Resource Center (Glenwood) in Glenwood, Iowa and Woodward Resource Center (Woodward) in Woodward, Iowa. Glenwood houses 163 residents and Woodward houses 122 residents. Many Resource Center residents can be served in their homes and communities with appropriate services and supports, and do not oppose doing so.

Yet, the State has acknowledged that important services and supports are often unavailable in the community. Iowa also fails to provide Resource Center residents and their guardians with sufficient information about community options. This information is necessary for an informed choice about where to live and receive services.

In sum, Iowa's system of care requires people with IDD to live in segregated facilities to receive the services they need and for which they are eligible under Medicaid. This segregation is unnecessary and violates the ADA.

II. INVESTIGATION

On November 21, 2019, DOJ notified Iowa of DOJ's intent to investigate Glenwood and Woodward, two State-run, residential facilities for people with IDD. We conducted two on-site visits of Glenwood and extensive interviews by videoconference. We also reviewed thousands of documents produced by the State. On December 22, 2020, DOJ notified Iowa that there is reasonable cause to believe that conditions at Glenwood violate the federal rights of the people living there and that these violations are pursuant to a pattern or practice of resistance to the full enjoyment of rights protected by the Fourteenth Amendment to the United States Constitution (December 22, 2020 Report).

Specifically, DOJ concluded that Iowa operates Glenwood in a manner that has subjected its residents to unreasonable harm and risk of harm, in violation of their Fourteenth Amendment rights, by exposing them to:

- Uncontrolled and unsupervised physical and behavioral experimentation;
- Inadequate physical and behavioral health care; and

- Inadequate protections from harm, including deficient safety and oversight mechanisms.

DOJ continued to investigate the ADA issues that apply to both Resource Centers. DOJ attorneys and an expert consultant conducted an extensive review of State-produced documents and conducted dozens of additional interviews. We interviewed multiple employees from each of the two Managed Care Organizations (MCOs) providing long-term services and supports in Iowa, Glenwood and Woodward social work staff, and leadership and staff across several divisions of the Iowa Department of Human Services. We also spoke with community-based providers, other entities involved in Iowa's community-based system for people with IDD, family members and guardians of Resource Center residents, and people seeking services. Additionally, we observed annual support planning meetings for many current Resource Center residents, reviewed related planning documents, and held related meetings with residents, their guardians, and Resource Center and MCO staff.

We would like to thank the State for the assistance and cooperation extended to us throughout our investigation, and to acknowledge the courtesy and professionalism of all the staff and counsel involved in this matter. We also thank the residents and family members who spoke with us and welcomed us into support planning meetings.

III. IOWA'S SERVICE SYSTEM FOR PEOPLE WITH IDD

Many people with IDD need long-term services and supports to assist with their personal and health care needs, and to live more independently. Iowa's Medicaid program funds such services in home and community-based settings for qualifying people with IDD. It also funds these services in institutional settings, such as the State-operated Resource Centers, private Intermediate Care Facilities for Individuals with an Intellectual Disability (ICF/IID), and nursing facilities. The State's Department of Human Services, which includes the Iowa Medicaid Enterprise, is the "single state agency" responsible for administering the State's Medicaid program. *See* 42 C.F.R. § 431.10.

Since April 1, 2016, Iowa has operated a managed care program, called the "IA Health Link," to deliver health care to the majority of Iowans eligible for Medicaid. Under Iowa's program, Iowa Medicaid Enterprise contracts with MCOs to deliver Medicaid health services.[1] Most Medicaid recipients with IDD, including people who receive long-term services and supports, are served by the MCOs.

A. State Resource Centers

Both Glenwood and Woodward are licensed under Medicaid as ICF/IIDs, which are institutions specifically designed to serve people with intellectual disabilities and other related

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[1] MCOs receive a monthly capitation payment, which is a predetermined amount of money paid by the State on behalf of each enrollee, to cover the cost of providing covered services. The actual services beneficiaries receive during the covered period do not affect the amount paid.

conditions. 42 U.S.C. § 1396d(d)(1).[2] Federal regulations require ICF/IIDs to provide each resident with "a continuous active treatment program." This is defined as the:

> aggressive, consistent implementation of a program of specialized and generic training, treatment, health services and related services . . . directed toward (i) the acquisition of the behaviors necessary for the client to function with as much self-determination and independence as possible; and (ii) the prevention or deceleration of regression or loss of current optimal functional status.

42 C.F.R. § 483.440. To that end, the Resource Centers provide medical services, nursing services, physical and occupational therapy, nutrition management, psychiatric services, mental health and behavioral support services, residential, vocational and day programming, and other services to residents.

Combined, the Resource Centers house 285 people. Many of them have complex behavioral or medical needs. The youngest resident is 16 years old, and the oldest is 88. Their average age is 50 years old. Most have lived in the Resource Center for decades. The average length of stay is approximately 28 years, and more than 40 percent of the residents have lived there for 30 or more years. All Resource Center residents have a legal guardian who is responsible for making decisions regarding their care, welfare, and safety. Iowa Code Ann. § 633.635.

As described in our December 22, 2020 Report, DOJ has investigated the Resource Centers before. In summary, DOJ concluded in 2002 that conditions at Glenwood and Woodward were constitutionally deficient. In 2004, DOJ and Iowa entered a settlement agreement to guide reforms at Glenwood and Woodward. The agreement also required Iowa to take several actions to "encourage and assist people to move to the most integrated settings" appropriate (2004 Agreement). Iowa came into compliance with the 2004 Agreement, and it terminated in 2010.

B. Other Institutional Settings

In addition to the Resource Centers, approximately 1,800 Iowans with IDD live in private ICF/IIDs. These facilities range in size from 4 to 96 beds. Over one quarter of the ICF/IIDs in Iowa are large facilities, with capacity for 18 or more people. Today, Iowa is among the five highest utilizers of this kind of institution in the United States.[3] The number of Iowans served in

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[2] Although admission to the Resource Centers requires diagnosis of an intellectual disability, many residents also have related disabilities that require similar services. Throughout this letter, we use the term IDD in order to include individuals with intellectual disabilities who also have related conditions such as Cerebral Palsy. *See* 42 C.F.R. § 435.1010 (defining "related condition"); Iowa Admin. Code r. 441.83.60 (same).

[3] In 35 states, between 0 and 25 people with IDD live in an ICF for every 100,000 people. Iowa is one of only five states with more than twice that rate of ICF utilization: It houses more than 51 people per 100,000 in such institutions.

ICF/IIDs has stayed essentially constant since 1982. By contrast, the number of people served in such institutions nationally has declined by almost 50 percent.

Iowa also has 431 nursing facilities that range in size from 16 to 702 beds, with an average bed-size of 68. While Iowa is unable to report a precise number, public reporting shows between 598 and 1,000 people with intellectual disabilities, related conditions, or both, live in Iowa's nursing facilities. Even the most conservative of these estimates leaves Iowa with the fourth highest rate of nursing facility utilization for people with IDD in the United States. Separately, public reporting shows that an additional 274 Iowans with IDD are living in psychiatric facilities.

C. Community-Based Services

Iowa provides Medicaid home and community-based services to people with IDD using both Medicaid State Plan and Medicaid waiver programs.

Like nearly all states, Iowa operates "home and community-based services" (HCBS) waivers that create a package of Medicaid-reimbursable community-based services for people who have long-term care needs that otherwise would qualify them for institutional care. 42 C.F.R. § 430.25(2). One HCBS waiver program, Iowa's Intellectual Disability (ID) waiver, provides services for almost everyone leaving the Resource Centers.[4] The ID waiver funds a range of services to support people with IDD in the community,[5] but it does not cover certain essential services, including critical mental health and behavioral support services.

The State also offers certain services through its Medicaid State Plan, which may be combined with waiver services when necessary. These include rehabilitative services, such as physical therapy, occupational therapy, speech therapy, and dietician or nutritional services. The State's Medicaid State Plan also provides some critical behavioral support services such as Applied Behavioral Analysis, discussed in Sections III.D and IV.C.2.b below. However, these services are only available to a subset of the population based on criteria that exclude many people currently living in the Resource Centers. By contrast, the Resource Centers provide such services based upon a person's need and do not have such exclusions.

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[4] The ID waiver is the largest of Iowa's seven waivers, serving roughly 13,000 individuals. It is also the only waiver solely for people with a diagnosis of intellectual disability. However, people with IDD may also receive waiver services through other waivers, such as the HCBS Brain Injury waiver or the Health and Disability waiver.

[5] Services under the ID waiver are available to Iowans of all ages who meet certain income guidelines and are determined to need an ICF/IID level of care. Waiver services include adult day care, consumer directed attendant care, day habilitation, home and vehicle modification, home health aide, interim medical monitoring and treatment, nursing, personal emergency response, prevocational, respite, supported community living, supported community living-residential based, supported employment, transportation, financial management services and independent support brokerage services, personal care, individual directed goods and services, and self-directed community and employment supports. *See* Iowa Department of Human Services, Home- and Community-Based Services Intellectual Disability Waiver Information Packet, https://perma.cc/EB75-CBP3.

In addition, Iowa's Mental Health and Disability Services (MHDS) system provides locally delivered services, managed by 14 geographic regions according to statewide standards. The regions are required to ensure that a core set of mental health and disability services are available for adults with a mental illness or disability.[6]

D. Money Follows the Person

Iowa began implementing a Money Follows the Person (MFP) Demonstration grant in 2008. MFP is a federal program that seeks to increase home and community-based services and reduce institutionally based services. Iowa's MFP Demonstration grant was initially intended to help Iowans move out of ICF/IIDs and into community homes of their choice. Iowa later expanded the MFP target population to serve additional people who live in a broader range of institutions.

MFP provides increased funding for transition services and enhanced supports needed for the first year after someone moves from an institution to the community. This additional assistance is available to Iowans who have a diagnosis of an intellectual disability or brain injury, have lived in an ICF/IID or nursing facility for at least three months, and have expressed an interest in moving into the community.

In 2012, the MFP program contracted with a behavioral specialist to provide Positive Behavior Support training and consultation to providers, people receiving services, and families who are assisting a person who may be experiencing challenging behaviors. Positive behavioral supports are research-based strategies, derived from Applied Behavioral Analysis, that build upon the person's preferences and needs to decrease problem behaviors while enhancing their personal satisfaction, social interactions, and quality of life. Between 2015 and 2020, 33 people transitioned from the Resource Centers using MFP. This is an average of five to six people per year.

IV. FINDINGS

We conclude that there is reasonable cause to believe that the State fails to provide services to people with IDD in the most integrated setting appropriate to their needs as required by the ADA. *See* 42 U.S.C. § 12132; 28 C.F.R. § 35.130(d). The State plans, administers, and funds its public healthcare service system in a manner that unnecessarily segregates people with intellectual disabilities in the Resource Centers, and almost certainly many other institutions,

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[6] This includes assessment and evaluation, case management, crisis evaluation, day habilitation, family support, health homes, home and vehicle modification, home health aide, job development, medication prescribing and management, mental health inpatient treatment, mental health outpatient treatment, peer support, personal emergency response system, prevocational services, respite, supported employment, supportive community living, and 24-hour access to crisis response. Iowa Admin. Code r. 441-25.2(331). In addition, as of July 1, 2021, the regions are required to make available additional intensive mental health core services, including an array of mental health crisis response and sub-acute services, and "intensive residential service homes" (IRSH). Iowa Admin. Code r. 441-25.3(3)(331).

rather than providing these services where people live, in their community. *See* 28 C.F.R. § 35.130(b), (d).

A. Legal Framework

Congress enacted the ADA in 1990 "to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities." 42 U.S.C. § 12101(b)(1). Congress found that "historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem." 42 U.S.C. § 12101(a)(2). Accordingly, the "ADA is intended to insure that qualified individuals receive services in a manner consistent with basic human dignity rather than a manner which shunts them aside, hides, and ignores them."[7]

Under Title II of the ADA, public entities must "administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." 28 C.F.R. § 35.130(d); *see also* 42 U.S.C. § 12101(b). The most integrated setting appropriate is one that "enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible." 28 C.F.R. Pt. 35, App. B. The regulations also require public entities to make reasonable modifications in policies, practices, or procedures when necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that such modifications would fundamentally alter the nature of the service, program, or activity. 28 C.F.R. § 35.130(b)(7).

In *Olmstead v. L.C.*, the Supreme Court applied these authorities and held that public entities are required to provide community-based services to people with disabilities when (a) such services are appropriate; (b) the affected people do not oppose community-based services; and (c) community-based services can be reasonably accommodated, taking into account the resources available to the entity and the needs of other people with disabilities. 527 U.S. 581, 607 (1999). The Court explained that unnecessary institutionalization "perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life." *Id.* at 600. The Court also recognized the harm caused by unnecessary institutionalization when it found that "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment." *Id.* at 601.

If a state fails to reasonably modify its service system to provide meaningful alternatives to institutional care, it violates Title II of the ADA. *Olmstead*, 527 U.S. at 607; 28 C.F.R. § 35.130(b)(7). The ADA's integration mandate applies both to people who are currently institutionalized and to people who are at serious risk of unnecessary institutionalization.[8] The

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[7] *Helen L. v. DiDario*, 46 F.3d 325, 335 (3d Cir. 1995).

[8] *See Steimel v. Wernert*, 823 F.3d 902, 911-12 (7th Cir. 2016); *Davis v. Shah*, 821 F.3d 231, 262-64 (2d Cir. 2016); *Pashby v. Delia*, 709 F.3d 307, 321-22 (4th Cir. 2013); *M.R. v. Dreyfus*, 663 F.3d 1100, 1115-18 (9th Cir. 2011), *amended by* 697 F.3d 706 (9th Cir. 2012); *Fisher v. Okla. Health Care Auth.*, 335 F.3d 1175, 1180-82 (10th Cir.

State also has a separate legal obligation to ensure the availability of community-based services provided under its Medicaid State Plan. The State must ensure that those State Plan services are available with reasonable promptness statewide to everyone who meets Iowa's Medicaid eligibility criteria. 42 U.S.C. § 1396a(a)(8), 42 C.F.R. § 435.930 (with reasonable promptness); 42 U.S.C. § 1396a(a)(1), 42 C.F.R. § 431.50 (statewide). Because the State already must make these services accessible statewide, meeting this obligation is inherently reasonable.

Even when the State contracts with MCOs to administer its Medicaid program, the State retains ultimate responsibility under the ADA.[9] The State also remains responsible for ensuring that people enrolled in Medicaid receive medically necessary services.[10]

B. Iowa's Resource Centers Are Segregated Institutions

Iowa's Resource Centers are institutions: They are public intermediate care facilities for individuals with intellectual disabilities, which by definition are institutions licensed under Medicaid to serve people with IDD. 42 U.S.C. § 1396d(d); 42 C.F.R. § 400.200; *see also King v. Fallon*, 801 F. Supp. 925, 929 (D. R.I. 1992) (ICF/IID placement is "the most restrictive option, requiring residential commitment to a public or private institution"). Iowa acknowledges that these facilities are not integrated, community-based settings.

Like other types of institutions, the Resource Centers offer few opportunities to interact with people without disabilities other than paid staff. *See* Section IV.C.1.b.ii below.[11] Most

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2003); *United States v. Mississippi*, 400 F. Supp. 3d 546, 553-54 (S.D. Miss. 2019) (collecting cases); *Hiltibran v. Levy*, 793 F. Supp. 2d 1108, 1115-16 (W.D. Mo. 2011). A state's failure to provide community services may create a risk of institutionalization. *Pashby*, 709 F.3d at 322; *Fisher*, 335 F.3d at 1182 ("[F]ailure to provide Medicaid services in a community-based setting may constitute a form of discrimination."); *see also Radaszewski v. Maram*, 383 F.3d 599, 609 (7th Cir. 2004) ("[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.").

[9] 28 C.F.R. § 35.130(b)(3)(i) (a public entity may not, "directly or through contractual or other arrangements, utilize criteria or methods of administration . . . [t]hat have the effect of subjecting qualified individuals with disabilities to discrimination on the basis of disability").

[10] *See* 42 U.S.C. §§ 1396-1 (purpose of Medicaid), 1396a(a)(5) (state must designate a "single State agency" to run its Medicaid program); 42 C.F.R. § 431.10; *K.C. ex rel. Africa H. v. Shipman*, 716 F.3d 107, 116, 118 (4th Cir. 2013) (single state agency requirement "embodies an important accountability rationale: Congress's desire to prevent states from backsliding on their Medicaid obligations by deferring to the nonconforming actions of other agencies" or by "simply contracting away [the state's] duties" to MCOs) (citation omitted).

[11] *See Frederick L. v. Dep't of Pub. Welfare*, 364 F.3d 487, 491 (3d Cir. 2004) (the most integrated setting appropriate for an individual, as opposed to institutionalization, "enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible"); *Murphy v. Harpstead*, 421 F. Supp. 3d 695, 715-16 (D. Minn. 2019) (citing evidence that integration "is about making informed and free choices about with whom one lives and about where and with whom one spends their time" and "means that an individual is a part *of* the community rather than simply *in* the community").

aspects of Resource Center residents' daily lives, such as bathing, meal, and medication times, are highly regimented.[12]

C. Iowa's Administration of the Resource Centers and Its Long-Term Care Service System Leads to the Needless Segregation of Individuals with IDD

Roughly a decade ago, Iowa acknowledged its high reliance on ICF/IIDs as "one of the most significant elements of institutional bias in its disability service system." In its 2007 application for an MFP Demonstration Grant, the State described a "pervasive attitude" that for people with IDD, "placement in institutions – including large institutions – is the best way to ensure their health and safety," and recognized that differential reimbursement for institutional versus community-based services favor keeping people in institutions.

In planning for its MFP Demonstration, Iowa identified several significant barriers contributing to this institutional bias, including:

> (1) a lack of awareness of, or even misinformation about, community living alternatives;
>
> (2) the scarcity of assistance from trained professionals in planning for and accomplishing successful transitions; . . .
>
> (3) an underdeveloped HCBS provider network;
>
> (4) the absence of critical services such as crisis intervention and behavioral supports; and
>
> (5) inflexibility in program funding, which makes it difficult for many individuals, particularly in rural areas, to find the supports they need.

Despite some efforts to address these issues through MFP and other initiatives, the same problems remain today. Iowa continues to rely heavily on institutions to provide services and supports to people with IDD. *See* Sections III.B and IV.C.2.a. Critical community services and supports – including the crisis intervention and behavioral supports identified a decade ago – are still underdeveloped. *See* Sections IV.C.2.b-d below.

The State acknowledges that it must develop community supports equivalent to the specialty services offered in its Resource Centers. Without this, people with IDD (including guardians acting on their behalf) lack a meaningful choice to live in a community-based setting. We heard from many concerned family members about previous negative experiences in the community, in which insufficient supports and staffing contributed to crises, police involvement, or their family members being removed from their homes. According to the State, these experiences have "fracture[d] confidence" in community services.

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[12] *See Disability Advocates, Inc. v. Paterson*, 598 F. Supp. 2d 289, 322 (E.D.N.Y. 2009) (citing "rigid schedules" for meals and medication as one factor indicating an institutional setting).

Further, Iowa has neglected work that is critical to accomplishing successful transitions from the Resource Centers. Staff and stakeholders told us that, before the current investigation began in late 2019, community transitions from the Resource Centers were not a priority. As described below, staff do not have sufficient knowledge about currently available community living alternatives to educate guardians and residents. Relatedly, the State has failed to implement consistent service and transition planning processes that are concrete, individualized, and proactive, with defined roles among the several entities involved and oversight to ensure that transitions occur successfully. *See* Sections IV.C.1.b-c below.

As a result, community transitions from the Resource Centers have declined, from about[13] 31 in 2010 and 36 in 2011 to only 5 in 2018, 7 in 2019, and 10 in 2020. In the past four years, the combined monthly average census went from 368 people in January 2017 to 300 in January 2021. This decrease includes not only community transitions, but also transfers to other facilities and deaths. In fact, during the past four years, the facilities' mortality rate exceeded their transition rate. Senior officials acknowledge that the pace of transitions is "slower than anyone would have wished for."

1. Resource Center Residents Can Receive Appropriate Services in Their Own Homes and Communities and Do Not Oppose Doing So

a. Resource Center Residents Can Be Served in the Community

People currently living in the Resource Centers could live in integrated community homes if they received appropriate services and supports there. This is so even though many residents also have behavioral or medical conditions that are complex or chronic, and require corresponding supports like behavioral support services, counseling, crisis services, nursing, and habilitative therapies. Some residents need staff present at all times in their homes, and residents who are non-ambulatory need wheelchair-accessible housing. In addition, many residents receive support with activities of daily living, such as bathing, dressing, and managing medication, among others. But with access to these services and supports in the community, they could live in their own homes, instead of an institution.

It is well established that people with IDD can live successfully in their homes and communities with appropriate services and supports. This includes people with highly complex medical and behavioral support needs. The State agrees. In fact, multiple State officials told us that anyone with IDD can live in the community with such services and supports. And the Iowa Department of Human Services has concluded that:

> Across the nation [people with multiple complex needs] are often safely, appropriately, and successfully served in intensive integrated service settings that have a combination of 24 hour, seven day a week staffing supervision and guidance, and extensive professional treatment and oversight. Iowa needs to increase the number of and statewide access to effective and efficient services such as these.

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[13] These numbers are approximate because there were some small discrepancies in the State's data.

With the assistance of an expert, we attended many Resource Center residents' support planning meetings; interviewed several of those residents, their guardians, and Resource Center staff; and examined related State records. We determined that all of those residents could live in the community with appropriate supports. Moreover, like all people, they have a wide variety of needs, interests, preferences, and strengths that life in the community could help them advance. For example, some wanted to see their families more often, build relationships with others, do things in the community whenever they wanted, work in the community, and continue their education.

Residents remain at the Resource Centers because the State has failed to provide sufficient information about community options, or because the available options are insufficient. For example, M.P.[14] is a 27-year-old woman who has lived at Glenwood since 2012. She would like to live in the community with fewer people in the household and eventually closer to her family. She hopes to take art classes, sell her art, and work at a grocery store, daycare, or nursing home. Glenwood determined that she needs few supports, and in 2020, placed her on the waitlist for a community waiver home operated by the State. The staff determined that this environment would be much less stressful for her than Glenwood. But her prospects for moving are unclear, because there is a waitlist for State-operated waiver homes, and the Resource Center had not identified other options for her. M.P. told us that she has already been waiting to move for years.

Another resident, O.H., is a 54-year-old man who has lived at Glenwood since he was five. Although O.H. has significant disabilities, staff indicated that he could easily be served in the community with appropriate services and supports. Although he is nonverbal and has not been identified by the State as someone who has requested to move, a staff member told us that she thought he would like having a private area to call his own. At Glenwood, he lives with about 13 other people and has engaged in self-injurious behaviors that staff anticipate would decrease if he lived someplace quieter. The State's records show that O.H. enjoys getting out of the facility, eating out, and going to the mall, the movies, and the zoo, among other activities, but he had a total of 14 community outings for the entirety of 2019. When we spoke to his guardian, she was unaware that his needs could be met in the community and expressed interest in receiving more information.

At Woodward, E.T. is an 18-year-old resident who loves music and can play the keyboard and the guitar. He could live in a home in the community with appropriate services and supports, but like most other Resource Center residents, he rarely leaves the facility. From October 2019, shortly after he came to Woodward, to February 2020,[15] he had six community outings. E.T. wants to live in the community, and the State is aware of his preference. But his

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[14] All residents discussed in this Report are identified using random pseudonyms. We will separately send, under seal, a key containing their true names.

[15] Due to limitations on community activities during the COVID-19 pandemic, this letter describes the frequency of activities before the start of that period in March 2020.

social worker has not identified a provider ready to serve him, and she told us that providers she contacted said their waitlist was four to six years long.

People with complex medical needs could leave the Resource Centers and live in the community with appropriate supports. For example, F.B. is a 56-year-old woman who has lived at Woodward since she was four years old. Staff recognize that she appears to enjoy events off campus, but she attended a total of 11 off-campus activities during all of 2019. Further, she lives with 11 other people, and staff reported that a potential benefit of her moving to a home in the community is that she would probably receive more staff attention and have more opportunities to get outside the house and go on community activities. Although F.B. is non-ambulatory and receives nutrition and medications through a G-tube, she could live in the community with the right services and supports, including sufficient staff and nursing care, and a home that is accessible for her wheelchair and other adaptive equipment. In Woodward's assessment, her barriers to living in the community were both the "severity of her health needs as it is difficult to find a provider that has 24/7 nursing care," and guardian reluctance, which was in part due to concerns about care. Despite the challenge involved in finding an appropriate placement, her social worker told us that she is sure people with characteristics like F.B.'s are living successfully in the community.

b. Many Resource Center Residents and Their Guardians Do Not Oppose Community Transitions

According to the State's reports, many Resource Center residents already have indicated they would prefer to receive services in the community, and have legal guardians who do not oppose transition. Many of the remaining Resource Center residents and their guardians have not had the opportunity to make an informed and meaningful choice to oppose community options. First, Iowa lacks an adequate array of community services that could meet the needs of Resource Center residents. Where a state fails to make adequate and appropriate community services available for a person, the person's alleged "choice" to enter or remain in an institution is not a meaningful choice to "oppose" community services under *Olmstead* or the ADA's integration mandate.[16] Second, Iowa fails to provide adequate, individualized information about community options, on a regular basis, in a way that residents and their guardians can understand and meaningfully consider.[17]

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[16] *See, e.g.*, *Olmstead*, 527 U.S. at 593, 603 (Court held that plaintiff EW did not oppose community integration when EW refused inappropriate discharge from an institutional setting to a homeless shelter and remained institutionalized); *Kenneth R. v. Hassan*, 293 F.R.D. 254, 270 n.6 (D.N.H. 2013) ("[T]he *meaningful* exercise of a preference will be possible only *if* an adequate array of community services are available . . . ."); *Messier v. Southbury Training Sch.*, 562 F. Supp. 2d 294, 331, 342 (D. Conn. 2008) (considering the actual availability of placement opportunities as relevant evidence in determining whether guardians had made an informed choice to oppose community placement).

[17] A person's "preferences may be 'conditioned by availability, . . . limited by information, and are likely to evolve in a system that complies with the ADA.'" *Kenneth R.*, 293 F.R.D. at 270 n.6 (quoting plaintiffs' brief). Thus, concluding that people oppose community services when they have not had sufficient opportunities to understand their options thwarts the purpose of *Olmstead* and the integration mandate. *See Disability Advocates, Inc. v. Paterson* ("*DAI II*"), 653 F. Supp. 2d 184, 260-67 (E.D.N.Y. 2009), *vacated on other grounds*, 657 F.3d 149 (2d

Courts have recognized the importance of providing "concrete options for placement" rather than an "abstract possibility that [the person] could live in a more integrated setting," with enough individualized information and opportunities to ensure they understand the options available.[18] Even where a person's guardian is the legal decision maker, the person's opinions and preferences should be considered.[19] Consequently, people with disabilities and their guardians cannot be said to oppose community services simply because they have not expressed a preference about transition.[20]

i. Many Residents Have Already Expressed an Interest in Moving

According to the State's records, at least a quarter of Resource Center residents have requested to move to homes in the community. The State has already determined that more than half of these residents' guardians do not oppose transition.[21] These reports undercount the number of people who may prefer community-based services. For example, they only include requests to move from people who can verbally make those requests, a shortcoming State officials acknowledged.

Several people whom the State identified as requesting to move have a strong and persistent preference for the community. Some have been waiting for years to move. One Woodward resident, L.B., and his guardian have been seeking community-based services since 2012. A Glenwood resident, M.P., told us that she had wanted to move for at least a couple of years. Although her social worker reportedly had not identified any options for her, she had

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Cir. 2012) (finding that plaintiffs were not opposed to community services where there was "convincing evidence that many would choose to live in [the community] if given an informed choice," and explaining that for people who had been institutionalized for a long time, it was common to be fearful, reluctant, or ambivalent about transition without additional assistance).

[18] *Messier*, 562 F. Supp. 2d at 333-34, 337-42.

[19] *See Messier*, 562 F. Supp. 2d at 336-37 ("Guardianship does not completely divest a[n] . . . individual [with IDD] of the right to participate in decisions," and "professional standards require that the opinion of an individual with [IDD] be taken into account in making community placement decisions.").

[20] *DAI II*, 653 F. Supp. 2d at 263 (noting the percentage of people "who reported a preference to move out of their adult home is merely 'a floor' with regard to who would truly be willing to move if given the proper 'encouragement,'" including information and support in making "a true choice"); *Messier*, 562 F. Supp. 2d at 337-38 (finding that state could not "establish compliance with the integration mandate by showing that class members never requested community placement").

[21] As described in Section IV.C.1.b.iii below, Iowa tracks the number of Resource Center guardians it considers to be "reluctant" about transition. But the reported reluctance occurs in the context of many flaws in the State's service and transition planning processes and in the community-based service array, which prevent an informed and meaningful choice to oppose community services.

taken it on herself to identify a potential provider and had shared that information with her social worker.

Another Woodward resident, S.M., said that he wanted to live in the community to have more freedom, and that he had always wanted to move. Despite having experienced repeated denials from providers, he had not given up on his goal. We also encountered a Woodward resident, E.T., who had been admitted in 2019 and said he wanted to move. He had previously visited a more integrated setting in 2018 and reportedly liked it so much that he had wanted to stay there that day.

The State recognizes that many guardians who are responsible for residents who have requested to move, including the guardians of L.B., S.M., and E.T., do not oppose the receipt of services in the community. We found that additional guardians of residents, such as M.P.'s guardian, share the resident's interest in receiving some form of community services or have not had the opportunity to make an informed choice to oppose such services.

The Resource Centers make limited efforts to identify community service options for residents whose guardians have not agreed to explore those options, even when those residents want to leave. Staff sometimes also suggest to residents that their desired community home or activities may be unavailable without knowing about, or exploring, alternatives that might meet the residents' needs and preferences.

For example, one Glenwood resident, D.C., reportedly has talked about wanting to live in the community since arriving at the facility in 2007, although his interest wavers when staff warn him that he might not be able to do things he likes in the community. Ironically, Glenwood's records showed he had not been able to participate in all his desired activities while living there, stating: "Know that [D.C.] likes to go out and he would prefer to go on every activity but he has to take turns with his roommates. Encourage him to get involved with playing board games with peers on the weekends so he is not so bored." But his social worker failed to explore community options that might sufficiently address his preferences.

Another Glenwood resident, E.W., told his social worker and his MCO case manager that he would like to live with his sister. But that apparently is not an option, and his Glenwood social worker told us he became disinterested in exploring community alternatives when she told him so. By contrast, his MCO case manager told us that E.W. had indicated that if he could not live with his sister, he would want to live nearby in a smaller home, with a provider who could meet his needs. Yet, neither the social worker nor the MCO case manager had looked for such a provider.

ii. The State Has Not Adequately Informed Resource Center Residents About Community Options or Evaluated Their Preferences

Iowa's service and transition planning processes are insufficient to ensure that Resource Center residents have made an informed choice about where they receive services. Staff make inadequate use of strategies to aid decision making and communication of preferences, such as opportunities to visit homes in the community. For example, Glenwood staff told us that a

Glenwood resident, M.H., would need to experience being in a home to convey if that were where she would like to live. And Woodward staff told us that it would be "very beneficial" for R.H., a Woodward resident we reviewed, to visit alternatives to the Resource Centers to see what they are like, rather than only hearing verbal descriptions from staff. Consistent with these observations, an expert hired by the State to review practices at Glenwood recommended in May 2020 that staff facilitate visits for residents and their guardians to different community settings.

Yet, the Resource Centers rarely provide these or other opportunities for people to experience or learn about community options. This is despite the Resource Centers' proximity to homes operated by the State, including near Glenwood and Woodward. Our review of numerous individual support plans made clear that residents are unlikely to visit a community provider until they and their guardians are already pursuing community transition. In fact, no residents whose plans we reviewed had visited a community provider in the preceding ten years if they had a guardian identified as "reluctant," effectively blocking an informed choice to oppose community services. Further, their individual support plans typically lacked goals to visit homes. Even residents whose guardians support transition rarely visited providers, likely diminishing their ability to choose specific settings that would best align with their needs and preferences.

Residents also lack regular opportunities to spend time outside the facility, engage with people in the community, and experience a variety of community activities, which are critical to ensuring informed choice because they allow residents to develop knowledge and preferences related to community living. As a State official acknowledged to us, it is the Resource Centers' responsibility to promote interactions with the community and access to the many activities that are not available in an institutional setting. However, while residents have had some access to community activities, such as shopping, visiting museums, and going to the zoo, these outings have been infrequent for many.[22] Further, as staff told us, they tend to be group activities with other Resource Center residents. These activities are unlikely to preview the natural flow of daily activities, spontaneous interactions with other members of the community, and sense of belonging that people living in the community can experience.

Most individual support plans we reviewed did not have goals related to experiencing life in the community, although many residents reportedly enjoyed community activities and had certain activities they preferred. Even when individual support plans discussed community activities, the discussion almost never addressed how those activities would be facilitated or how often. Despite these issues, the State official responsible for overseeing the Resource Centers told us that he was not planning to implement any recommendations to improve community participation.

Finally, we found that many individual support plans at both Resource Centers did not build on residents' strengths, interests, and preferences. Most residents' goals focused on

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[22] We found that community activities were already infrequent before the onset of the COVID-19 pandemic.

reducing negative behaviors, doing house chores, or attending to personal hygiene. These goals did not speak to residents' positive attributes, activities they enjoyed, or larger goals they had in life.[23] It was within this context that residents were denied opportunities to shape their futures, including whether to receive community-based services.

iii. Guardians of Many Resource Center Residents Do Not Oppose Community Transition

The State has already identified dozens of guardians who are not opposed to community services, and our review found other guardians who have made statements and taken actions showing they are willing to consider options for community placement. For example, the guardian for one resident, B.C., while not yet ready for her daughter to move, has been working with the Resource Center and the Money Follows the Person program to explore community options. She told us that she had wanted her daughter to live in the community but had given up after she was unable to find suitable placements and her daughter appeared to do well at the Resource Center. She told staff that she was interested in attending presentations by providers, noting "maybe the programs have changed and I need to get with the program." The guardian for another resident, O.H., told us that she did not think there was a provider that could meet O.H.'s needs, but if such a provider existed, she would be interested in learning more. We also met the guardian for a resident named G.R., who indicated she was open to community providers as long as the provider could meet G.R.'s needs. If a provider were capable, she said, "then I am absolutely fine with him moving." Another guardian had placed his daughter, M.P., on the waitlist for a State-operated waiver home.

Further, although the State reports that a majority of guardians are "reluctant" about community transition, our investigation indicates that guardians rarely have the opportunity to make an informed and meaningful choice to oppose receiving community-based services. Many guardians' reluctance is due to concerns about the State's failure to ensure that critical services offered by the Resource Centers are sufficiently available in the community.

In addition, we observed many lost opportunities to understand, and potentially address, guardians' concerns. For example, the State could develop strategies for anticipating and responding to issues that might arise as part of a transition and create concrete plans for transition that take into account the concerns of guardians. Discussion of such strategies with guardians, however, was not common at the support planning meetings we attended, nor evident from the planning documents we reviewed. Agreements allowing residents to return to the Resource Center if a community placement is unsuccessful may also help guardians make the decision to transition. The State recently reinstated a prior policy allowing for such agreements, but the effectiveness of that initiative remains to be seen.

Also, the State could provide guardians with information about a range of homes in the community and other services that could support a person, suggest that guardians visit

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[23] When examining practices at Glenwood, the State's consulting expert similarly determined that individual support plans "did not have goals/objectives that were important to the person's interests."

community homes that align with the person's preferences and needs, and offer ways for guardians to meet with families of people who have recently transitioned. Until our investigation began, the State seldom engaged with guardians about community options more than once a year, when social workers raised the general topic of transition as part of an extensive list of topics addressed in residents' annual planning meetings. And among the people we reviewed, many guardians had still received little information about community options.

Staff often provided no information to guardians about suitable community options because staff had not identified those options. Rather, staff typically began the exploration of community options by asking guardians if they would like to consider community living options. If the guardian said "no," the process stopped before it could begin, with no comprehensive search conducted. Independently, the State's expert found regarding Glenwood that, "[i]f a guardian was against possible discharge, the discussion ended without review of possible options. There was no attempt to educate the individuals' family or guardians on available community options, facilitat[e] visits to different community settings . . . or consult[] with providers regarding the services available within the community."[24]

The State reports recent efforts to increase engagement with guardians, but ultimately, there has been no meaningful difference for many Resource Center residents and their guardians. Among the people we reviewed, most guardians the State identified as reluctant about transition still had not received information about concrete, individualized options. Most guardians of the residents we reviewed had not visited providers, as the State typically had not identified community placement options. Many guardians had not met with families of people who have moved to the community and have similar characteristics and needs as the person for whom they are responsible. Thus, the State has not used strategies known to help guardians make informed choices about community transition. And new resources the State developed to inform residents and guardians about community transition have been insufficient.[25]

iv. Staff Lack the Information and Resources Needed to Ensure Informed Choice and Achieve Timely Transitions

Organizational problems compound the State's failures to ensure informed and meaningful choices, and achieve timely transitions. The State has tasked social workers with leading these efforts, but historically it has not given them the resources to do this work.

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[24] To the extent the Resource Centers have shared information about providers with guardians, these communications have been infrequent or lacking in individualization. For example, for the residents we reviewed, Woodward annually sent lists of providers that were not tailored to the needs of residents, and sporadically – usually not more than once a year – sent information about openings with providers.

[25] For example, in 2021, the State published an online guide to community resources, but this was simply a list of programs and organizations without the individualization residents or guardians would need to envision a community transition. On the topic of community providers, the guide was not helpful because it directed readers to a list of mental health and disability service providers in Iowa that did not differentiate services by type of disability or specify the types of services providers offered beyond very general categories.

Multiple staff responsible for transitions lack familiarity with current community options. Senior officials acknowledge that relevant Resource Center staff, particularly at Glenwood, have not visited community homes recently and are poorly informed about the nature of community services and supports. This makes it difficult for them to understand and explain what services are available, thus limiting the kinds of options staff seek and suggest for residents.

Also, despite senior officials' acknowledgement that anyone can live in the community with appropriate services and supports, staff at multiple levels still view improvements in skills and behavior as relevant to a person's readiness to move to the community. In fact, this view is incorporated in the Resource Centers' new transition planning guidance, which indicates that the first stage of transition for all residents is "Stabilization & Skill Building," so that "the person is ready for community-based settings."

This misplaced emphasis on skill-building as a precursor to transition is due in large part to the perceived unavailability of community services, discussed in Section IV.C.2 below. As a senior official responsible for developing the transition guidance explained, the presumption is that everyone who enters an ICF/IID needs to develop skills to be successful in the community. He noted that people would not need to be institutionalized for that reason if the State had sufficient services and supports in the community, but "[w]e don't have that at the level we need."

Separately, the State lacks an effective strategy to identify or develop individualized community options. The primary method for identifying community options for individual residents consists of sending an anonymized synopsis of a resident's needs, with guardian consent, to multiple providers to see if any might be interested in receiving more information about the resident, who is not identified. But as one senior DHS official observed from her previous role with an MCO, building relationships with providers works to develop appropriate options. Sending anonymized referrals does not. Further, the practice may preclude staff from developing information upon which undecided or reluctant guardians could make an informed choice.

A lack of role clarity regarding key aspects of transition planning further impedes the process. Social workers, MCO case managers, and, in some instances, MFP staff share responsibility for engaging with residents and guardians about community services, identifying options, and planning for transition. State officials acknowledge that the responsibilities of each remain unclear. The lack of coordination contributes to deficient information sharing and support planning.

The State does not conduct meaningful oversight to ensure individual service and transition planning and education about community options are being delivered properly and effectively by staff at the Resource Centers. The senior State staff charged with monitoring these areas do not collect the necessary feedback to know, for instance, the frequency and adequacy of information residents and their guardians receive about community services; whether residents have meaningful opportunities to participate in community life; and whether staff are consistently addressing guardians' concerns about transition. So, the State cannot know whether it is moving forward in building a system that enables people to live successfully in the community.

In addition, Iowa has failed to ensure that the MCOs transition people out of the Resource Centers in a timely and effective way. For instance, Iowa's MCO contracts do not condition payments to the MCOs on their success in enabling people to move from facilities (the Resource Centers and others, such as nursing facilities) to community-based services that meet their needs. Although the State says it plans to implement such pay-for-performance measures, there is no specific timeline for doing so. And currently, the only information the MCOs must report about this issue compares the proportion of people who are receiving long-term services and supports in the community to the proportion receiving those services in a facility. This measure does not differentiate by population, so it is not possible to know what proportion of Iowans with IDD rely on facilities to receive these services, the types of facilities they reside in, or whether these figures are changing over time. The MCOs have developed voluntary incentive programs for providers to support people who would be transitioning from Resource Centers, but these initiatives are just getting started and are not driven by the State. The State acknowledges a need to increase its oversight of the MCOs, with enforcement authority and financial incentives tied to MCO performance.

c. Deficiencies in Iowa's Service and Transition Planning Processes Impede Timely and Successful Transitions to Home and Community-Based Services

Iowa does not have a consistent statewide protocol for developing transition plans, either as to what specific planning documents must be completed or what substantive information must inform the transition planning, particularly for behavioral supports. As a result, residents often have multiple plans that let significant issues fall through the cracks. Separate plans are typically developed by the Resource Center, MFP staff, and sometimes the MCO, each of which is not consistently informed by the others. There is no comprehensive plan driving the process.

Iowa's transition planning is not person-centered.[26] The transition plans we reviewed reflect a move from one building to another, not a plan to build a life for each person in the community that reflects what is important to them (such as preferences for activities, food, and people to spend time with) and important for them (such as the supports they need to maintain health and function well in the community). Also, for people with past trauma, transition plans should recognize that experience to identify how prior trauma may affect current behaviors, treat the trauma, and ensure that services are trauma-informed and do not trigger traumatic

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[26] Person-centered planning is important in enabling successful transitions and ensuring community integration. *See, e.g.*, 42 C.F.R. § 441.301(c)(1), (4) (HCBS waivers) (The person-centered planning process, which is meant to enable a person to be as fully integrated in the community as possible, must "[p]rovide[] necessary information and support to ensure that the individual directs the process to the maximum extent possible, and is enabled to make informed choices and decisions . . . ."); *Murphy*, 260 F. Supp. 3d at 1101-1103, 1113-16 (plaintiffs had adequately pled ADA integration mandate claim where they claimed injury due to isolation and segregation, which may be remedied in part through individualized services, "including person-centered planning").

experiences. Given the high rate of trauma among people with IDD, this gap is particularly concerning.

Even when other Resource Center records contain information about the person's preferences, the ultimate transition plan does not include concrete steps to ensure those preferences are implemented in their future life in the community. The transition is focused on finding a vacancy with a provider who will accept the person and assumes they will go to an existing group home, rather than developing a plan that best suits the person. And even for people who said they wanted to work, their transition plans did not prioritize setting up employment in the community, other than a reference to connecting them with vocational rehabilitation. This lack of person-centered planning means the person is less likely to have a full and integrated life in the community; risks destabilizing the person, given the lack of consistency between the Resource Center and the new home; and may cause harm, such as if the person is placed with people who are not a good fit.

The transition plans also fail in some cases to identify the kinds of supports a resident would need in the community, such as appropriate living arrangements, counseling, behavioral supports, or a crisis plan distinct from routine behavioral interventions. Further, even when Resource Center records reflect the need for such supports, planning documents do not reliably incorporate them in an effective way. In addition, these planning documents do not consistently account for environmental differences between an institution and the resident's community home, as well as changes in behaviors discovered after the move.[27] Inadequate planning and behavioral supports have consequences: A senior State official acknowledged that when a community-based provider lacks sufficient information about how to meet someone's behavioral needs, behaviors may arise that the provider is unprepared to manage, leading the provider to discharge the person, seek hospitalization, or call the police.

In addition, the State does not have processes to ensure consistent monitoring of people in transition, so as to confirm that they are safe and receiving appropriate services. The template documents that MCO case managers use for follow-up visits after these transitions are not structured to ensure the visit detects problems with the transition, health and safety issues in the home, or additional necessary services. For instance, the documents provide space for "observations" of areas such as physical condition or mood, but no direction about what issues to monitor, either for that person specifically, or for people with IDD generally. And there is no backstop: The State does not confirm that, absent such guidance, MCO case managers have the background or experience to identify issues in a client's home or any missing supports needed for the person to remain in the community.

The State does not ensure that MCO case managers have sufficient expertise in the needs of people with IDD. Although training is available, there is no required number of hours or curriculum for a case manager to complete. The State does not check whether case managers have an appropriate caseload or are ensuring their clients receive adequate services in the

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[27] The Money Follows the Person program will fund revisions to behavior support plans, but the program is thinly staffed, and providers inconsistently use that assistance.

community. As noted in Section IV.C.3 below, the State's provider oversight process does not include regular in-person visits to these homes, and the State does not otherwise have a system to oversee reliably the quality of community-based services. Overall, the State's lack of oversight of the transition process, MCO case managers' work, and community-based services leaves the State unable to ensure that people with IDD are receiving the services necessary to avoid institutionalization.

2. Iowa Has Failed to Address Known Deficiencies in the Availability of Community-Based Services and Supports that Contribute to Needless Institutionalization of People with IDD

Iowa offers an array of services and supports that support Iowans with IDD in their homes and communities. Indeed, many Iowans – including those with high support needs similar to some Resource Center residents' – are already receiving services in the community. However, the lack of adequate community alternatives, particularly for people with more complex medical and behavioral needs, prevents this outcome for many Resource Center residents. Although the State has known for years that its community service system is insufficient, it has failed to meaningfully assess and correct the deficiencies.

a. Iowa Relies Heavily on Institutional Settings to Serve Individuals with IDD

As addressed above, Iowa uses ICF/IIDs and nursing facilities to house people with IDD at very high rates compared to other states. *See* Section III.B above. At the same time, the State has failed to meaningfully invest in community services. This is reflected in the disproportionate reimbursement rates for community providers, which place them at a disadvantage when compared to State institutions that offer higher wages and a better benefits package. According to a 2020 Iowa Association of Community Providers Wage Survey, the average direct support professional's starting wage is $11.98, about one dollar more than the starting wage at a fast food chain and commensurate with grocery cashiers. By contrast, the starting wage for a direct support professional at Woodward Resource Center is $17.96. This disparity makes it comparatively harder to staff community settings.

This imbalance is also not new. As early as 2007, Iowa acknowledged that its underdeveloped network of home and community-based services for people with IDD was "due in part to the fact that facility-based service providers receive higher reimbursement rates than community service providers," and that "skilled services tend to be easier to access in institutional settings."

During the course of our investigation, a senior official acknowledged that the State continues to invest more heavily in institutional care, creating "perverse incentives" to rely on it. As another senior official explained:

> When you look at the sheer numbers in the state of Iowa, the number of individuals we serve in institutional settings is high. Our balance is off. Further – our balance specific to the number of individuals who reside in state-run facilities is also high. There is a tremendous amount of work to do here.

Iowa's heavy reliance on institutional care is indicative of deficiencies in the community system, and it signals that many Iowans with IDD are unnecessarily institutionalized or at serious risk of institutionalization. According to the State's MFP program, "[f]amilies are frequently driven to place loved ones in ICFs/ID [sic] for lack of any apparent alternative." Reports that community providers often resort to involving the police, or discharging people to hospitals or other institutional settings, reinforce these concerns.

Meanwhile, according to State reports, the number of applicants on the waiting list for ID waiver services has more than doubled in recent years: from 2,381 in January 2019 to 4,802 in May 2021. Accepting the State's estimate that approximately 26 percent of these people will be eligible for services, more than 1,000 eligible people may be waiting for necessary services today. This indicates that community services are insufficient to meet the need, which increases the risk that people will be placed in institutional settings such as the Resource Centers, private ICF/IIDs, and nursing facilities. State officials acknowledge that the length of the waiting list is concerning, but they are aware of no efforts to reduce it, aside from releasing slots that become available through attrition. Moreover, the State has not monitored the impact of its waiting list by, for example, evaluating how often people turn to institutional settings to receive the services they need. In fact, aside from the annual public reporting described above, the State is not even tracking the number or proportion of people with IDD who are in nursing facilities, psychiatric facilities, or private ICF/IIDs. Nor has the State established any goals or performance benchmarks regarding the number or proportion of people it intends to serve in such institutions.

b. Iowans with IDD Are Often Unable to Access Critical Mental Health and Behavioral Supports in Community Settings

For years, the State has reported that a majority of Resource Center residents face barriers to community placement due to behavioral support needs. According to the State, this is one of the most common barriers to moving to the community among Resource Center residents. The State counts this as a barrier for people if it has determined that they need a higher level or frequency of behavioral supports than is "commonly offered by community providers." Such behaviors are not uncommon for people with IDD and often serve to communicate unmet needs or soothe an individual in distress or pain. But positive behavior supports reduce or eliminate challenging behaviors in most people. *See* Section III.D above.

Positive behavioral supports are a type of Applied Behavioral Analysis that emphasize improvement in the quality of life for the person with disabilities and for people who support them. They may include psychological and functional behavioral assessments, the development of a behavior support plan, and positive behavior training for support staff and family members. According to the State, such supports are provided in the Resource Centers. The importance of access to these supports is both generally accepted in the field and embraced by Iowa's Money Follows the Person program.

In addition, people with IDD often have co-occurring mental health disorders, such as major depression, bipolar disorder, and anxiety disorders, as well as histories of trauma. This is true for many Resource Center residents. These conditions may cause, or complicate the treatment of, challenging behaviors and can lead to behavioral crises. Treatment may include common psychotherapeutic approaches adapted to the person, such as cognitive behavioral therapy, peer and group supports, and medication. Many states also offer crisis services to people with IDD to address acute and urgent mental health needs: services that are often critical to avoiding institutional admissions.

With access to appropriate services and supports, the behavioral needs of people living in the Resource Centers should not bar successful community living.[28] But according to State reports, the percentage of Resource Center residents who could not access the behavioral supports they need in the community is rising, from 60 percent in 2014 to 68 percent in 2018 and 2019. The State further notes that this "rise for many years is a reflection of the practice that people moving into the Resource Centers are those for whom a state-wide search results in no community provider available."

State officials acknowledge the inadequacy of community-based mental health and behavioral support services for Iowans with IDD, including insufficient access to Applied Behavioral Analysis and to crisis and de-escalation supports. Further, State reports acknowledge that the "cost and ability to hire and maintain staff and training to provide these supports at the frequency, consistency, or level of need for the individuals served in the [Resource Centers] often can be a challenge, especially for community providers."

Consequently, many providers are unable to serve people with more complex behavioral needs. They often lack the necessary clinical expertise and struggle to obtain needed supports elsewhere. While some external assistance with behavioral supports is available, it is not sufficient to meet the need. For example, Iowa's Technical and Behavioral Supports Program (I-TABS) program offers some technical assistance through peer review of behavior support plans and training on behavior support strategies. State officials say that the scope of this assistance is quite limited and, while they support expanding the reach of the program, they lack the staff to do so.[29] Iowa's Money Follows the Person program also offers positive behavioral supports training, as well as on-site consultation and observation and development and training on behavioral plans. But the program employs only one full-time and one part-time staff member for this purpose. In addition to these staffing constraints, the MFP program reports that its effects are limited because providers continue to experience high turnover. Thus, staff trained to implement an individual's support plan may not be the staff who continue to work with the individual.

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[28] Our experts concluded that the Resource Center residents they reviewed, which included many with the most intensive behavioral needs, could be served in the community with appropriate supports and services. Many would not need supports beyond what is typical to be successfully integrated in the community. Further, people with needs like those of people with the most challenging behaviors in the Resource Centers are served appropriately in the community with a combination of behavioral supports, psychological (psychotherapeutic) services, and proper medications.

[29] Currently, I-TABS is managed by a staff member at Woodward who also bears significant interim responsibilities for the psychology departments at both Woodward and Glenwood, both of which have been operating without a psychology director for extended periods of time.

We spoke with some providers who employ staff with the clinical skills and credentials to perform necessary services in-house, including completing behavioral assessments, developing behavior support plans, and training staff to implement those plans. However, they are not reimbursed for these services. Few providers are able to offer these supports, and those that do say they could not accept new referrals without additional support from the State.

In a recent State survey, home and community-based providers frequently cited insufficient capacity to meet peoples' behavioral needs, including a lack of community behavior support services and higher staffing needs (such as the need for 1:1 or 1:2 staffing ratios), as the reason they had declined to serve Resource Center residents. Waitlists for the providers that do offer the level of support needed can be years long. This also has been the driving factor in recent Resource Center admissions. As one former senior official explained: "The settings aren't there for individuals with the most complex behavioral needs the way they should be." According to the former DHS director, those admitted to the Resource Centers in recent years had "nowhere else to go."

More broadly, without adequate mental health and behavioral supports, people who currently live in the community are at risk of police involvement, and/or discharge to hospitals or other institutional settings. Multiple stakeholders and State officials told us that providers lack the skills to support people with IDD who experience a mental health crisis and that, if the person's needs cannot be met within the home, the options are to call the police or take the person to the emergency room.

c. Despite Longstanding Knowledge of the Issue, Iowa Has Failed to Address Deficiencies in Its Service Array

State officials identified the lack of sufficient community-based behavior management, counseling, and crisis supports at least a decade ago. In planning for the implementation of its MFP Demonstration Grant, Iowa recognized that enhancement of the ID and Brain Injury waiver service menus "to include additional supports for individuals with mental illness or behavioral issues [was] widely regarded as one of the most important steps the State of Iowa could take to expand community living options."

State officials proposed that at a minimum, three services should be added to the ID waiver beginning in 2014: behavioral programming, mental health outreach, and crisis intervention services. They stated that the addition of these services would ensure sustainability for participants in the MFP program after their year of enhanced funding ends; "eliminate barriers to community living for many people besides MFP participants"; and "make permanent contributions to a rebalanced system."

Accordingly, the Iowa Medicaid Enterprise drafted proposed amendments to the Iowa Administrative Code to expand the package of services available under the ID waiver. The amendments would have allowed members to receive – and qualified providers to bill for – the three additional services referenced above (behavioral programming, mental health outreach, and crisis intervention services). Iowa Medicaid Enterprise noted that the additional supports were specifically intended to reduce involuntary discharges from community providers and to reduce the need to go to or return to a facility. Regardless of the recognized need, the State never implemented this proposal. Current officials cannot recall why, saying only that efforts to amend the waiver stalled in 2015.

Predictably, these deficiencies persisted, and so did the negative consequences. According to a Department of Human Services progress report regarding the Mental Health and Disability System, published in November 2016:

> Many service providers lack the capacity to successfully and effectively serve Iowans with the most serious service needs. Too many individuals are discharged from community placement when their needs exceed the providers' capability. These individuals are far too often admitted to in-patient psychiatric hospitals and, when they are ready to be discharged, have nowhere to go because of a lack of community-based providers with the capacity to successfully serve them.

Following this evaluation, and subsequent recommendations from a workgroup of stakeholders, the State initiated new efforts to develop services for people with complex needs. Specifically, Iowa enacted legislation that directs the 14 geographic regions to establish, implement, and maintain additional intensive mental health core services by July 1, 2021. Iowa Code Ann. § 331.397; Iowa Admin. Code r. 441-25.2(331).

Many of these services could provide useful support for people who are transitioning to the community from a Resource Center. In particular, Iowa State law requires the regions to develop an array of mental health crisis response and sub-acute services. The regions must also develop "intensive residential service homes" (IRSH), which would offer higher staffing ratios, 24-hour supervision, and clinical oversight of behavioral services and related trainings for staff. Iowa Admin. Code r. 441-25.6(8)(331).

However, several limitations prevent these services alone from filling the gaps described above. First, they were designed as mental health services, not services for people with IDD.[30] As a result, they poorly fit the needs of people with co-occurring diagnoses. Second, existing crisis providers[31] often refuse to serve people with IDD and may lack the skills to do so.

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[30] The intensive residential service homes are the only new core service that may offer ongoing behavioral supports to people with a primary diagnosis of IDD. This service is designed "to serve adults with the most intensive severe and persistent mental illness conditions." Iowa Admin. Code r. 441-25.6(8)(331). In addition, to be eligible, a person must meet several criteria, including either current institutionalization or out-of-state placement, a recent history of frequent institutionalization, or precarious housing. *Id*. Thus, these services are not an option for everyone who is moving out of a Resource Center, or at serious risk of institutionalization.

[31] Regions have already developed some required crisis services, like "mobile response" and "23-hour crisis observation and holding" in a psychiatric environment. Others, such as "crisis stabilization community-based services," which would offer short-term alternative living arrangements to de-escalate the situation and allow an individual to stabilize in the community "where the individual lives, works, or recreates," remain largely undeveloped. State officials say that crisis stabilization community-based services have been difficult for the regions and providers to understand.

Officials are aware that this is an ongoing issue. Yet, the State does not monitor whether core services are available for people with IDD when needed, or whether the services that are provided effectively address people's needs.

Finally, State officials asserted that Iowa has not been able to compel the regions to develop these new core services, and that the regions could not meet the July 1 deadline for certain required services – particularly intensive residential service homes and crisis stabilization community-based services. Although recently enacted legislation may empower the State to ensure that these services are developed,[32] the implementation and efficacy of the legislation remain to be seen.

d. Iowa Lacks the Capacity to Serve People with Complex Health Care Needs

Complex health care needs pose another common barrier to community integration. According to State reports, at least 22 percent of Resource Center residents "require specialized medical treatment and/or monitoring that is not readily available in the area of choice or the level of care they prefer." This percentage includes people who need assistance with monitoring and administering injections for diabetes, nutrition and medication via G-tubes, and fast and frequent access to monitoring and adjustment of adaptive equipment, and people with seizure disorders. At the Resource Centers, they are supported by professionals – including doctors, nurses, and physical, occupational, and speech therapists – who are available either on grounds or on call. Due to communication difficulties or the nature of their health complications, they frequently benefit from consistent staff who know them well enough to recognize subtle signs of discomfort or medical need. According to the same State reports, it is "difficult for many guardians to consider a move to a setting where those resources may not be as readily available."

Few providers serve people with such health conditions in Iowa. State officials and providers report that insufficient access to necessary medical supports, particularly nursing services, poses significant barriers. While Medicaid funding for a high level of nursing services is available in theory, officials acknowledge that obtaining it is "cumbersome." Beyond this, however, officials were unable to pinpoint the specific barriers to integration for people with complex health care needs, admitting that there has not been significant analysis of the issue.

e. Iowa's Failure to Evaluate its Community Service Array Contributes to these Longstanding Barriers

Although Iowa has known for years that community-based supports for people with complex medical and behavioral needs are insufficient, officials acknowledge that they have failed to meaningfully assess the capacity of the community service system. Prior to this investigation, the State relied on the MCOs' own reporting regarding network adequacy and anecdotal feedback about the community service array. Officials were not aware of any other

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[32] Officials report that the State's "county home rule" has precluded enforcement of these requirements to develop core services. In late May of 2021, the Legislature passed initiatives to enable the State to distribute funds for these services to the regions in accordance with performance-based contracts. *See* Iowa Code Ann. § 225C.7A. This was done in an effort to facilitate the development of a minimum level of services statewide.

data source used to assess the capacity of community services for people with IDD. Thus, while senior officials agree that they "absolutely have gaps," they lack the detailed information needed to understand and remedy them.

Overall, the State does not evaluate what services are delivered to people with IDD in order to identify systemic gaps, or otherwise assess at an aggregate level whether people with IDD are receiving services that are necessary to prevent institutionalization. For instance, Iowa does not receive reporting about whether people have sufficient access to crisis services, behavioral services, nursing, or enhanced staffing ratios.

Iowa also has not evaluated whether the structure of its own Medicaid program frustrates people's access to services, although that structure is difficult to use. For example, individuals enrolled in the State's ID waiver can draw from three different sources of funding for nursing, but each source has distinct billing requirements and service limits. This creates a complicated system for providers to navigate, but the State expects providers to do so with little support. Possibly as a result, there is disagreement between providers and the State about what funding is available for nursing services.

Providers would like to serve more people with complex needs but are reluctant to do so without assurance that they will obtain the needed supports, both at the outset and over the long term. As one provider put it: "We believe we can do more" to serve people living in the Resource Centers, "but you can only risk so much." The State's failure to support providers in accessing funding for those services that are available only further decreases the pool of providers capable of supporting people with more complex needs.

Since this investigation began, the State has taken preliminary steps to assess and identify gaps in its community services. State officials say they hope to conduct a full-scale review of Iowa's Medicaid waivers, including the menu of services and rate structure, by 2022. However, this work largely has not yet begun, and the timing remains uncertain.[33] While all of the contemplated reviews may provide critical information that guides the development of needed services, the adequacy of the evaluation, and any real changes that may result, have yet to be seen.

In summary, although the State has known for years that vital supports to serve people with complex needs were needed, it has failed to modify its Medicaid service system to ensure that they are available for people in the community. Rather, many Iowans with IDD who use Medicaid have only been able to access these services in institutional settings like the Resource Centers.

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[33] In addition, the State has not evaluated whether previous improvement efforts were effective. For example, in March 2019, recognizing that providers were struggling to support people with multiple complex needs, Iowa increased the reimbursement rate for people in the highest "tiers" – those determined to have the highest support needs – and decreased it for people in the lowest tiers. But Iowa has not evaluated the impact of these changes. And providers report that, at their current rates, it is still very difficult to maintain the stable workforce needed to serve people with complex medical and behavioral needs. We spoke with several who said this could prevent them from expanding their services or accepting other people from the Resource Centers.

3. Iowa Exercises Insufficient Oversight of MCOs and Home and Community-Based Services to Prevent Unnecessary Institutionalization

The State does not exercise oversight of MCOs or community providers to ensure people with IDD have access to sufficient services to avert the risk of unnecessary institutionalization. First, the State does not verify MCO-reported data, and the State acknowledges this makes it more difficult to hold the MCOs accountable for meeting people's needs. Second, there is no plan in place to use MCO-reported data more effectively.

As noted above, the State is only beginning to evaluate in a systemic way what services or providers are missing, and Iowa does not collect much of the data that would be necessary to do so. In particular, the State has delegated to the MCOs its responsibility to develop a community-based provider network without overseeing what the MCOs are, or are not, doing to build the community service array. And the State does not track, or require the MCOs to gather, the information necessary to ensure this provider network is sufficient to meet people's needs.

In addition, the State fails to use available information to evaluate whether people are at serious risk of institutionalization. For instance, the MCOs must report a list of people whose services they have reduced or terminated so a sample may be audited. But Iowa does not assess whether those people were harmed by the service decision, including whether it led to people being institutionalized or placed at serious risk of institutionalization, or otherwise track trends in these service decisions.[34]

The State also does not assess why people who are receiving services seek additional support, or experience crises. For example, the State does not regularly review data about requested or authorized exceptions to the State's standard Medicaid caps to determine: why such additional resources were necessary; areas for possible improvement, such as a service limit increase; or outcomes for people whose requests for such resources are denied, including whether they must move to a more restrictive setting.

In addition, the State is not automatically notified, nor must the MCO report, if a provider leaves someone with IDD at an emergency room. The State typically finds out about such "emergency room discharges" only if the hospital calls. The State acknowledges its responsibility for ensuring the MCOs arrange for services so that community providers do not discharge people with IDD to the hospital. Iowa, however, does not review service plans after an emergency room discharge to see whether the person's services should be changed to meet an unaddressed need and avoid another hospitalization.

State oversight of providers of community-based services is also lacking, relying largely on self-reporting and incidental reports of problems. Several entities – different parts of State government, its quality assurance contractor, and the MCOs – receive data on providers'

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[34] The State MCO Ombudsman's Office, which assists people enrolled in the ID waiver and other Medicaid waivers, reports that service denials, reductions, and terminations have consistently been one of the top issues leading to calls for the Office's advocacy over the last several years. Stakeholders note these service cuts can put people at risk of institutionalization.

performance. The State has only recently started to discuss how to share disparate sources of information in order to further oversight, with no decisions yet made. The State does not regularly inspect the homes where people receive supported community living services for health or safety issues. Although providers must attest to whether they have policies and procedures in certain subject areas, including discharge, restraint, and seclusion, the State does not review these policies or provide sufficient standards to govern them substantively.

The State office that credentials providers only recently began to receive the quality assurance contractor's quarterly reports, which contain high-level measures of community service delivery and incidents. Iowa also does not receive regular reports on instances of neglect, abuse, restraint, or seclusion in provider settings. In fact, the MCOs are not required to collect this information, and when the MFP program relays issues with community providers to Medicaid, it does so on a case-by-case basis. Also, the State does not track, or require the MCOs to report, any health risks or outcomes more prevalent in people with IDD, such as choking, dysphagia, or trauma.

D. Iowa Can Reasonably Modify Its Service System to Serve People with IDD in Integrated Settings

Courts have found proposed modifications that expand existing services to be reasonable, particularly when the modifications align with the jurisdiction's own stated plans and obligations.[35] In addition, courts have acknowledged that a State may be required to provide a service in the community that is "in substance" already provided in an institution, even if the format in which it is delivered in the community is different.[36] The State may also be required to implement reasonable modifications – such as expanding community-based services – even if that requires increased financial resources in the short term.[37]

The State can reasonably modify its service system to support people with IDD in the community. Iowa already funds a range of services in the community, but these services are not available throughout the State or in sufficient quantities, and some have disability-based

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[35] *See, e.g.*, *Henrietta D. v. Bloomberg*, 331 F.3d 261, 280-81 (2d Cir. 2003) (upholding as a reasonable modification an order requiring agency to follow existing law and procedures); *Guggenberger v. Minn.*, 198 F. Supp. 3d 973, 1030 (D. Minn. 2016) (providing Medicaid waiver services to eligible people, particularly from existing waiver funds, is a reasonable modification); *Hiltibran*, 793 F. Supp. 2d at 1116 (a state providing a specific Medicaid service for people in institutions must provide it for Medicaid enrollees who need it in the community); *Haddad v. Arnold*, 784 F. Supp. 2d 1284, 1304-05 (M.D. Fla. 2010) (providing a service already in state's service system to additional people is not inherently a fundamental alteration); *Messier*, 562 F. Supp. 2d at 344-45 (plaintiffs' requested service expansion, which was consistent with defendants' publicly stated plans, was reasonable).

[36] *See, e.g.*, *Radaszewski*, 383 F.3d at 611 (comparing "the equivalent of around-the-clock, private-duty nursing care" in an institution, even if that did not mean 1:1 staffing, to a full-time nurse provided to one individual at home).

[37] *Frederick L.*, 364 F.3d at 494-96 (collecting cases); *Mississippi*, 400 F. Supp. 3d at 577 (collecting cases).

eligibility restrictions. It is reasonable for the State to expand the availability of services already on its menu to reach people who need them.

In fact, Iowa spends significant resources on institutional care, even though State data show that it is less expensive, on average, to provide community-based services rather than institutional services. The most intensive service available under the ID waiver, supported community living (SCL), provides up to 24 hours of support per day and costs between $68,883 and $226,895 per year, depending upon the level of supports and services received. By contrast, the average cost of care at a Resource Center is 40 percent more expensive than the most intensive community care, at $374,855 per year, or $1,027 per day.[38] State officials and stakeholders agree: In addition to the individual benefits of community living, supporting people to live in the community often saves money. It's "just smart."

It is reasonable for the State to analyze where there are deficiencies and imbalances in its service array, and whether current service delivery mechanisms or payment structures block access to existing services. It is also reasonable for the State to use this data to set goals for concrete, measurable progress toward a robust community-based system. The State is beginning to do this, but it lacks the data and analytical capacity necessary to ensure people are receiving sufficient services in the community. *See* Section IV.C.2.e above.

The State can reasonably modify its practices to ensure that people receiving services in institutions, and their guardians, make an informed choice as to whether they oppose receiving community-based services. Proven strategies exist to aid the decision-making process. They include providing visits to homes in the community, facilitating meetings with peers and family members who have experienced a transition, and providing other opportunities to experience community activities and develop preferences.

Person-centered service and transition planning processes are also critical to understanding and implementing individual's preferences, and ensuring informed choice. Such processes maximize people's participation in decisions about their lives and respect their interests, preferences, and autonomy. Iowa can ensure that an individual's service plan identifies, beginning at admission, the community components that are important for the person (including location, living arrangement, services and supports, and preferred activities), as well as what is available in the community (including the specific placement options that would address their needs and preferences).

The State can also modify its transition planning process to ensure it is robust, enables people in institutions to move to integrated community homes with services and supports that meet their needs, and results in the reliable delivery of sufficient supports in the community.

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[38] Also, while available data prevent a direct comparison, data provided by the State for 162 Resource Center residents indicates that 70 individuals, or 43 percent, would receive SCL services costing between $68,883 and $99,349 per year, while the remaining 92 individuals would receive SCL services at a cost of $169,725 to $226,895 per year.

It is reasonable for the State to develop solutions for situations when an MCO has exhausted existing strategies for finding a community-based setting for a facility resident, including making a long-term commitment to fund a provider (above the typical rates if necessary) and better supporting providers in meeting complex needs. Further, it is reasonable for the State to oversee its community-based service system to ensure that it provides appropriate oversight of MCOs and providers to meet the needs of people with IDD and minimize their risk of harm.

The State has been aware for years that its community-based service system for people with IDD has significant deficiencies. While Iowa has made preliminary efforts to improve this system, most of them started after this investigation began, and progress has not been sufficient to ensure access to services for those who need them to leave institutions or to avoid institutionalization.

The State's "Community Integration Strategic Plan," introduced in June 2020, is illustrative. It identified necessary steps over several years to ensure current Resource Center residents, and those who could seek admission, have the opportunity to live in the "least restrictive setting." These steps include:

- developing individualized support plans for current Resource Center residents;
- educating residents and guardians about available community supports;
- actively planning to transition people to the setting of their choice;
- assessing several aspects of the community service array; and
- developing robust community supports equivalent to current Resource Center services.

These are reasonable steps for the State to take. But the State's Strategic Plan lacks sufficient details and metrics to ensure it is effective, and its implementation is far from complete. For example, the Plan called for the State to finish developing a "work plan with measurable objectives and deadlines for ensuring community supports are safe, effective, and of high-quality" by October 2020, but work plan development was still continuing as of this Report's preparation. Also, the State planned to develop additional State-operated waiver homes – small residences where admission is prioritized for people leaving a Resource Center – across the state by April 2021. But this project had not yet started as of this Report's preparation. The State now intends to start it after evaluating the need to strengthen other services system-wide. More broadly, the State's work correcting acknowledged inadequacies in community-based services has already experienced delays for several years.

V. RECOMMENDED REMEDIAL MEASURES

The State should promptly implement measures to remedy the deficiencies discussed above and protect the civil rights of individuals with IDD who are in, or at serious risk of entering, Resource Centers or other institutional settings, such as nursing facilities and large ICF/IIDs. These remedial measures should include the following:

- Increasing community capacity by expanding services and removing restrictions on community services for people living in, or at serious risk of entering, Resource Centers or other institutions. The State must conduct reliable analyses to identify and remove barriers to accessing community services that result in people's placement in institutional settings. Individuals and their guardians must have a meaningful choice to receive services in the most integrated setting appropriate to their needs.

- Developing and implementing an effective system to disseminate information about community services, identify individuals in Resource Centers who are appropriate for and do not oppose community placement, identify individualized community options, and plan for and facilitate successful transitions. The State must ensure that Resource Center residents and their guardians have the opportunity to make an informed choice about where they receive services. All residents must have individualized, person-centered, written service and transition plans that identify the services and supports needed to successfully serve the person in the community.

- Ensuring that people who have transitioned from institutions to the community and those who may be at serious risk of institutionalization are receiving necessary services and supports in sufficient quantity and quality to enable them to succeed in the community and to maximize integration within the community.

- Ensuring adequate oversight of Managed Care Organizations, the MHDS Regions, and community providers, and adequate coordination among these entities, hospitals, and law enforcement, to avoid unnecessary institutionalization and to ensure individuals' safety and well-being.

VI. CONCLUSION

For the foregoing reasons, we conclude that there is reasonable cause to believe the State fails to provide services to people with IDD in the most integrated setting appropriate to their needs, in violation of the ADA. 42 U.S.C. § 12132; 28 C.F.R. § 35.130(d). The State plans, administers, and funds its public healthcare service system in a manner that unnecessarily segregates people with intellectual disabilities in the Resource Centers, and almost certainly many other institutions, rather than providing these services where people live, in their community. *See* 28 C.F.R. § 35.130(b), (d).

We look forward to working cooperatively with the State to reach a consensual resolution of our findings. We are obligated to advise you that if we are unable to reach a resolution, the United States may take appropriate action, including initiating a lawsuit, to ensure the State's compliance with the ADA.