



U.S. Department of Justice

Civil Rights Division

Office of the Assistant Attorney General

Washington, D.C. 20530

**MAY 02 2016**

Governor Dennis Daugaard  
Office of the Governor  
State of South Dakota  
500 East Capitol Avenue  
Pierre, South Dakota 57501

Re: United States' Investigation, Pursuant to the Americans with Disabilities Act, of South Dakota's Use of Nursing Facilities to Serve Individuals with Disabilities

Dear Governor Daugaard:

We write to report the findings of our investigation of South Dakota's system of care for individuals with disabilities who receive services and supports in nursing facilities. We find that the State does not comply with Title II of the Americans with Disabilities Act of 1990 ("ADA"), 42 U.S.C. §§ 12131-12134 (2006), as interpreted in *Olmstead v. L.C.*, 527 U.S. 581 (1999). In *Olmstead*, the Supreme Court held that individuals with disabilities are entitled to receive supports and services in the most integrated setting appropriate to their needs.

This letter describes the violations we identified and notifies the State of the steps it must take to meet its obligations under Title II of the ADA. By implementing the remedies set forth in this letter, the State will correct identified ADA deficiencies, fulfill its commitment to individuals with disabilities, and better use State and federal resources.

Before proceeding to the detailed substance of the letter, we would first 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 State officials and counsel involved in this matter to date. We appreciate that the State facilitated meetings with agency officials and staff and provided documents and information in response to our requests. We hope to continue our collaborative and productive relationship as we work toward an amicable resolution of the violations described below.

## I. SUMMARY OF FINDINGS

We conclude that South Dakota fails to provide services to individuals with disabilities in the most integrated setting appropriate to their needs, in violation of Title II of the ADA. Instead, South Dakota's system of care requires thousands of people with disabilities to live in segregated nursing facilities to receive the services they need and for which they are eligible

under Medicaid, despite their preference to remain in their own homes and communities. These individuals include those with physical disabilities, such as mobility limitations or blindness; chronic illnesses, like diabetes or heart disease; or cognitive disabilities, like brain injury due to stroke or trauma. They include younger and working-age people as well as older adults who have developed a disability as part of the aging process. Many of these individuals, and their families, have sought long-term care services from the State only to find that a nursing facility is the only available option. And many have never been informed by the State that they could be receiving care while living in their own homes.

Over the years, the State's own experts have determined that the State's long-term care system unnecessarily relies on institutional services. With adequate services, supports, and coordination, the State could successfully support individuals to remain in their homes and communities and could take advantage of the cost-effectiveness of community-based services. The systemic failure to provide critical home- and community-based long-term care services and supports also places individuals with disabilities who currently live in the community at serious risk of unnecessary institutionalization in nursing facilities.

Our specific findings include:

- Individuals with disabilities who rely on South Dakota's public healthcare system for essential services have little choice but to receive those services in nursing facilities. South Dakota has one of the highest nursing facility utilization rates in the nation. The State needlessly places South Dakotans with disabilities in nursing facilities because it does not sufficiently provide community-based services. Many South Dakotans who live in nursing facilities want to live in the community, where they can receive appropriate services. The State can serve people with disabilities in their own homes with appropriate services, but the State does not sufficiently make these services available.
- The State acknowledges that many South Dakotans want to receive services in their homes and communities and that providing such services is cost effective. Yet South Dakota has not significantly allocated resources toward home- and community-based services. Instead, South Dakota spends approximately 83% of its Medicaid long-term care budget on expensive nursing facility services – far above national norms. South Dakota has not taken advantage of federal funding opportunities to create additional cost savings for home- and community-based services.
- The State offers an array of services that could be used to provide home- and community-based support to most nursing facility residents with disabilities, but these services are not consistently available throughout the State. Further, unnecessary limits on these services undermine their effectiveness. When services are available, they are either capped or allocated in amounts that are often insufficient to support people in their own homes.
- Many people living in South Dakota's nursing facilities, as well as their families, are not aware that any home- and community-based services are available. Likewise, few think they have the option to choose to stay in their own homes. Because the State has not developed a system to immediately connect individuals with available alternatives when they seek or are referred to nursing facility care, most people never have a choice but to

enter a nursing facility. Similarly, the State has failed to develop a system to identify and provide transition assistance to nursing facility residents who can return home.

- The State's actions also put people with disabilities who live in the community at serious risk of unnecessary placement in nursing facilities. People who live in rural areas and Native Americans are at heightened risk due to a significant lack of home- and community-based services available to them.
- While some individuals may choose to live in nursing facilities, individuals in South Dakota do not have a meaningful option to receive services in the most integrated setting appropriate to their needs, because the State fails to offer sufficient services and has failed to develop systems that allow individuals to identify and select from among these services and settings. Similarly, while older adults who choose to live with others of the same age group should be able to do so, older adults with disabilities are often segregated together because of their disabilities.
- South Dakota's key agencies are well positioned to make essential changes. South Dakota's Department of Social Services already has systems that, if expanded and modified to effectively assist individuals in accessing services, could remedy the violations described in this letter. For example, the State already regularly reviews nursing facility residents for continued placement, but it does not appear to focus on home- and community-based alternatives in these reviews. Similarly, the State assesses those living in the community for long-term care services, but individuals are often placed in nursing facilities when the individual could be served at home. South Dakota can take advantage of and expand these and other existing systems to ensure that people with disabilities can receive the services they need in the most integrated setting appropriate.

The unnecessary segregation of people with disabilities in nursing facilities violates their civil rights and wastes the State's fiscal resources. Community integration with core services and supports will permit the State to support people in their homes and in their communities to achieve maximum independence, inclusion, and self-determination.

## II. INVESTIGATION

On August 11, 2014, we notified the State that we were initiating an ADA investigation into whether South Dakota unnecessarily institutionalizes individuals with disabilities in nursing facilities and places individuals with disabilities at serious risk of institutionalization. Our investigation focused on the availability of community-based, long-term care services for nursing facility residents and those at serious risk of nursing facility admission, including assistance with activities of daily living and instrumental activities of daily living; health care and rehabilitation services; and other supports to ensure that people with disabilities receive services in an integrated setting.<sup>1</sup>

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<sup>1</sup> Activities of daily living are mainly personal care tasks, such as bathing, dressing, eating, and using the toilet. Instrumental activities of daily living include household tasks such as shopping, cooking, and managing money. Individuals with disabilities can receive assistance with activities of daily living and instrumental activities of daily living from assistive personnel, whether in a nursing facility or at home. Health care services that

We visited the State four times, meeting with people who receive services and touring a range of healthcare facilities that serve people with disabilities. During the course of our investigation, we interviewed people living in nursing facilities across the State and administrators and staff at these facilities. We interviewed residents, administrators, and staff at numerous assisted living facilities. We also met with providers of community-based services, individuals with disabilities living in the community, and disability advocates and stakeholders. In addition, we heard from tribal leadership and tribal members from many of the Native American tribes in South Dakota. The State began providing requested documents and information in November 2014. In May 2015, we met with leadership from the Department of Health, Department of Social Services, and Department of Human Services.

### **III. SOUTH DAKOTA'S SERVICE SYSTEM**

South Dakota has a public healthcare system through which it delivers both Medicaid- and State-only-funded services to people with disabilities who meet medical and financial eligibility criteria. South Dakota provides for these services through certain State agencies, including the Department of Social Services, the Department of Human Services, and the Department of Health. The State makes services available primarily through nursing facilities as well as through certain Medicaid- and State-only-funded programs that provide some services in individuals' homes, in host homes, and in assisted living facilities. It also operates an Aging and Disability Resource Center program to connect individuals with these services and a Money Follows the Person program to facilitate discharges from nursing facilities. By expanding and addressing limitations in its existing community-based Medicaid services and programs that facilitate access to those services, the State can reduce its unnecessary reliance on expensive nursing facilities to serve South Dakotans with disabilities.

#### **A. Nursing Facilities**

South Dakota has 111 Medicaid- or Medicare-certified nursing facilities that range in size from 23 to 187 beds. Approximately 6,340 people reside in South Dakota's nursing facilities at a given time. The State finances the nursing facility placements through Medicaid for roughly 55% of these people – more than 3,400 individuals at a given time and roughly 5,500 individuals over the course of a year. While the majority of these residents are older than 75, almost 450 (13%) of those with Medicaid-financed stays at a given time are younger than 65, and over 160 people (5%) are younger than 55. Many of these individuals have disabilities they were born with or acquired at a young age, such as cerebral palsy, multiple sclerosis, amputations due to diabetes, or mobility impairments due to an accident.

As of February 2016, South Dakota has 6,878 licensed nursing facility beds. In 2014, South Dakota had an average nursing facility occupancy rate near 92% – a rate 10% higher than the national average. There is currently a statewide moratorium on new nursing facility beds;

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individuals may require include medication management, wound care, and nutrition services. Rehabilitation services include speech therapy, physical therapy, and occupational therapy. Individuals with disabilities can receive health care and rehabilitation services from licensed health care professionals such as nurses and therapists, whether in a nursing facility or at home.

however, the State Legislature has passed measures to give nursing facilities some flexibility to expand under certain circumstances.

## **B. Waiver Programs for Community-Based Services**

South Dakota operates four Medicaid waiver programs<sup>2</sup> as alternatives to nursing facilities or other institutions for individuals with disabilities who require long-term care. The Department of Social Services, through the Division of Adult Services and Aging, and the Department of Human Services maintain authority over the State's four waiver programs. According to the State, these programs are designed to "encourage support of individuals in their own home by offering home and community based services as an alternative to facility placement whenever feasible." Two of these programs, the Assistive Daily Living Services waiver (referred to here as the "Quadriplegia Waiver") and the Home and Community-Based Services waiver (referred to here as the "Home Services Waiver"),<sup>3</sup> are designed to provide community-based services to adults who would otherwise qualify for a nursing facility.<sup>4</sup> Neither of these programs has a waiting list, but both contain restrictions that limit their effectiveness at serving many people with disabilities in the community.

The Home Services Waiver is the State's primary service program for older adults and individuals with physical disabilities who would otherwise receive services in a nursing facility. *See* S.D. Admin. R. 67:44:03. It served 1,638 individuals in fiscal year 2014. Individuals can receive these services in their homes or in an assisted living facility. About 64% of people receive these services in assisted living facilities, and 36% receive services in their homes.

The services offered under the Home Services Waiver program include homemaker services; in-home nursing; personal care; respite for caregivers; companion services; physical adaptations to private residences; emergency response systems; meals and nutritional supplements; specialized medical equipment; adult day care; and, for individuals in some assisted living facilities, medication administration. While individual services do not contain specific caps, the State has chosen to limit the total cost of services in the program so that they cannot exceed 85% of the cost of nursing facility care.

The Quadriplegia Waiver program is also designed as an alternative to care in a nursing facility, but is limited to individuals who have a disability that affects all four limbs. *See* S.D. Admin. R. 67:54:06. In fiscal year 2014, 108 individuals received these services. The package

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<sup>2</sup> A Medicaid waiver program, authorized under Section 1915(c) of the Social Security Act, provides a package of services that allow people with disabilities to live in their homes or communities. Home- and community-based waiver programs create an alternative for individuals who would otherwise receive Medicaid State Plan services in a nursing facility or other institution.

<sup>3</sup> The Home and Community-Based Services waiver is sometimes also referred to as the Adult Services and Aging waiver.

<sup>4</sup> The State's other two waiver programs, the Family Support 360 waiver and the CHOICES waiver, are designed to provide community-based services to individuals with intellectual and developmental disabilities who would otherwise receive services in an Intermediate Care Facility. The services offered by one or both of the waivers include specialized medical and adaptive equipment, service coordination, respite care, nutritional supplements, companion services, environmental accessibility adaptations, supported employment, vehicle modifications, day habilitation, prevocational services, residential habilitation, and nursing.

of services offered through this program is similar to the Home Services Waiver, but personal attendant services are capped at 42 hours per week (about six hours per day).

### **C. Additional Community-Based Services**

In addition to waiver services, the State offers certain in-home services through its Medicaid State Plan and through State-only funding. Medicaid State Plan services may be combined with waiver services when necessary.

The State provides personal care services, which include homemaker and certain nursing services. *See* S.D. Admin. R. 67:16:24. Examples of these services include an aide or nurse who comes to the home to assist with bathing, dressing, medications, foot care, or meal preparation; and in-home household services such as housekeeping, laundry, and grocery shopping. The number of hours available for personal care, homemaker, and nursing services combined is capped at 120 hours per quarter, which equates to just over one hour per day. Of the 120-hour limit, nursing services are limited to 18 hours per quarter. In fiscal year 2014, only 514 individuals received Medicaid State Plan personal care services and on average, each individual billed only six hours per month.

The State also provides home health services. *See* S.D. Admin. R. 67:16:05. These services can include nurses or therapists who make home visits to provide skilled nursing and rehabilitative therapy, respectively. There are no unit limits on the number of hours of home health services an individual may receive, but the services must be intermittent, no more than once a day, and no more frequent than five days per week.<sup>5</sup> In 2014, 328 individuals received home health services through the Medicaid State Plan, and on average, each individual billed only 5.69 hours per month.

The State offers a host home model of care, called “adult foster care.” Adult foster care is a State-only funded, community-based, family-style residence that provides room, board, and general supervision of personal care tasks for no more than four individuals who have qualifying disabilities but do not require nursing services. There are currently approximately 35 host home beds licensed in 14 homes across the State. The services provided by those who oversee the home include companionship, hygienic assistance, laundry, and transportation.

Additional Medicaid State Plan and State-only funded community-based services include caregiver services and respite care,<sup>6</sup> telehealth, meals and nutritional supplements, emergency response systems, assistive devices, and medical transportation.

### **D. Money Follows the Person and Aging and Disability Resource Centers**

The State began implementing the Money Follows the Person Demonstration Grant in 2013 to provide opportunities for individuals to transition from nursing facilities and other institutions to person-centered home- and community-based services. The State was one of the

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<sup>5</sup> State regulations make an exception for more frequent visits “if the medical necessity for the multiple visits is documented by the attending physician in the individual’s medical record.” *See* S.D. Admin. R. 67:16:05:05(4), (5).

<sup>6</sup> Caregiver services are capped at a cost of \$5,000 per year.

last three states to both apply for and receive the grant. The program offers increased Medicaid funding and reimbursement for services that are not otherwise covered by Medicaid, technical assistance, and funding to strengthen state Aging and Disability Resource Centers.

South Dakota included adults living in a nursing facility for more than 90 days in its Money Follows the Person transition program target population. Individuals transitioning to the community under the program must reside in qualified housing in the community.<sup>7</sup> The program covers individuals' expenses associated with needed transition-related services, including crisis intervention, consumer preparation,<sup>8</sup> non-medical transportation, and miscellaneous transition costs, such as rental money and security deposits. The Department of Social Services administers South Dakota's implementation of Money Follows the Person.

To facilitate access to Medicaid services for individuals with disabilities, the Division of Adult Services and Aging developed Aging and Disability Resource Centers through a federal grant program. Referred to in South Dakota as Aging and Disability Resource Connections, the program is intended to be a "single point of entry for persons interested in long term services and supports." Adult Services and Aging Specialists represent Aging and Disability Resource Connections centers, and they are located in each of the 24 local offices throughout the State. Additionally, there are five Aging and Disability Resource Connections call centers in South Dakota that serve all 66 counties.

#### IV. FINDINGS

We conclude that the State fails to provide services to individuals with disabilities in the most integrated setting appropriate to their needs as required by 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 persons with disabilities in institutional nursing facilities, rather than providing services in community-based settings. *See* 28 C.F.R. § 35.130(b), (d). As a result, thousands of individuals with disabilities are needlessly living in institutions when they could receive the community services and supports available through South Dakota's public healthcare system.

Congress enacted the ADA in 1990 "to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities." 42 U.S.C. § 12101(b)(1). Congress found that "historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem." 42 U.S.C. § 12101(a)(2). For these reasons, Congress prohibited discrimination against individuals with disabilities by public entities when it provided that "no qualified individual with a disability

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<sup>7</sup> Qualified housing is (1) "a home owned or rented by the participant or the participant's family member;" (2) an apartment with an individual lease, including an apartment in an assisted living facility, so long as it has "lockable access and egress, as well as living, sleeping, cooking, and bathing areas over which the participant has domain and control;" or (3) a residence in a community-based residential setting in which no more than four unrelated individuals reside. S.D. Dep't of Social Servs., *South Dakota Money Follows the Person Operational Protocol Version 2.1* 61-62 (2014).

<sup>8</sup> Consumer preparation services provide Money Follows the Person participants with training and information needed to live safely at home.

shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity.” 42 U.S.C. § 12132. Accordingly, the “ADA is intended to insure that qualified individuals receive services in a manner consistent with basic human dignity rather than a manner which shunts them aside, hides, and ignores them.” *Helen L. v. DiDario*, 46 F.3d 325, 335 (3d Cir. 1995). The ADA protects anyone with a substantial limitation in a major life activity, including individuals who are limited in mobility, bathing, dressing, or eating due to a physical disability, and individuals who are limited in a major bodily function due to a chronic illness such as diabetes, stroke, arthritis, or cancer. 42 U.S.C. §§ 12102(1), (2); *see also Thorpe v. District of Columbia*, 303 F.R.D. 120, 127-28 (D.D.C. 2014) (“[I]t is reasonable to assume that most nursing facility residents are also individuals who satisfy the legal definition of an individual with a physical disability.”). The ADA’s protections therefore apply equally to older adults who acquire a disability through the aging process and to people who are born with or acquire disabilities earlier in life.

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)(1). The most integrated setting appropriate is one that “enables individuals with disabilities to interact with non disabled persons to the fullest extent possible.” 28 C.F.R. Pt. 35, App. B (2011). In *Olmstead*, the Supreme Court applied these authorities and held that public entities are required to provide community-based services to persons with disabilities when (a) such services are appropriate; (b) the affected persons do not oppose community-based services; and (c) community-based services can be reasonably accommodated, taking into account the resources available to the entity and the needs of other persons with disabilities. 527 U.S. at 607.

In so holding, 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. It 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.

The ADA prohibits “discrimination in the form of unnecessary segregation of those with disabilities in nursing homes and other institutions.” *Joseph S. v. Hogan*, 561 F. Supp. 2d 280, 285 (E.D.N.Y. 2008) (citing *Kathleen S. v. Dep’t of Pub. Welfare of Pa.*, 10 F. Supp. 2d 460, 468 (E.D. Pa. 1998)). A state is liable under the ADA where it administers its programs or services in a manner that unnecessarily segregates persons with disabilities in privately owned facilities. 28 C.F.R. § 35.130(b) (prohibiting public entities from using contractual arrangements, criteria, or methods of administration that have the effect of subjecting qualified individuals with disabilities to discrimination).

The ADA’s integration mandate applies both to people who are currently institutionalized and to people who are at risk of unnecessary institutionalization. *See Pashby v. Delia*, 709 F.3d 307, 321-22 (4th Cir. 2013); *M.R. v. Dreyfus*, 663 F.3d 1100, 1117-18 (9th Cir. 2011), *amended by* 697 F.3d 706 (9th Cir. 2012); *Fisher v. Okla. Health Care Auth.*, 335 F.3d 1175, 1181-82 (10th Cir. 2003); *Pitts v. Greenstein*, No. 10-cv-635, 2011 WL 1897552, at \*3 (M.D. La. May 18, 2011) (“A State’s program violates the ADA’s integration mandate if it creates the *risk* of

segregation; neither present nor inevitable segregation is required.”); *Marlo M. v. Cansler*, 679 F. Supp. 2d 635, 638 (E.D.N.C. 2010). 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.”); *Peter B. v. Sanford*, No. 10-cv-767, 2010 WL 5912259, at \*6 (D.S.C. Nov. 24, 2010) (“[A] State’s failure to provide services to a qualified person in a community-based setting as opposed to a nursing home or institution presents a violation of Title II of the ADA.”).

#### **A. South Dakota Nursing Facilities are Segregated, Institutional Settings**

*“I can’t sleep here. It’s not home.” – Nursing Facility Resident*

It is well established that nursing facilities are institutional, segregated settings. *See, e.g., Day v. District of Columbia*, 894 F. Supp. 2d 1, 22-23 (D.D.C. 2012); *Rolland v. Cellucci*, 52 F. Supp. 2d 231, 237 (D. Mass. 1999). Similar to psychiatric hospitals and other types of institutions, nursing facilities congregate residents together with other people who have disabilities; they offer few opportunities to interact with people without disabilities other than paid staff; and most aspects of residents’ daily lives are highly regimented. *Cf. Frederick L. v. Dep’t of Pub. Welfare of Pa.*, 364 F.3d 487, 491 (3d Cir. 2004) (citing 28 C.F.R. § 35.130(d) and 28 C.F.R. Pt. 35, App. A (1998)); *Benjamin v. Dep’t of Pub. Welfare of Pa.*, 768 F. Supp. 2d 747, 750 (M.D. Pa. 2011) (explaining that individuals in facilities were segregated when they lived in units ranging from 16 to 20 people, primarily received services on the grounds of the facilities, and had limited opportunities to interact with peers without disabilities); *Disability Advocates, Inc. v. Paterson*, 598 F. Supp. 2d 289, 321-22 (E.D.N.Y. 2009)).

Nursing facilities in South Dakota are institutions characterized by structures and rules that limit residents’ independence and community integration. Far more like a hospital than an individual’s home, nursing facilities are laid out with long hallways for residents’ rooms around central nurses stations and, in some cases, have locked doors or gates to prevent residents from leaving. Staff members wear uniforms and maintain separate office spaces that are off limits to residents. Staff members may typically enter rooms at any time after knocking on the door. Medicaid-funded residents rarely are permitted to have a private room or private bathroom, and they are often assigned to rooms with a roommate whom they do not choose. Common areas are usually impersonal public areas that more closely resemble a hospital lobby than a living room. Residents rarely have access to a kitchen where they can prepare their own food and are rarely permitted to do their own laundry. These characteristics are generally imposed on most residents simply by virtue of living in the facility and not by medical necessity.

The strict and methodical regulation of daily life in nursing facilities makes it practically impossible for residents to interact with people, other than staff, who do not have disabilities. Residents are subject to regimented bathing, meal, and medication times; and almost all residents see on-site doctors. In many facilities, residents are required to sign in and out, and in some cases, visitors must do so as well. Moreover, some facilities do not permit residents to leave the grounds unaccompanied, or they otherwise restrict where residents may go, even when this

limitation is not medically necessary for the individual. One 74-year-old resident explained that, as a result, when his friends come by and want to take him for a ride, “[t]hey have to sign me out, like a kid.” Nursing facility residents of working age do not typically have employment opportunities, which would allow them to interact with other members of their communities and to earn some income to support themselves. Instead, some nursing facilities occasionally allow residents to volunteer for menial, non-paying assignments. For example, one nursing facility staff member explained that a 55-year-old female resident was allowed to do office work in exchange for a lollipop and water.

When residents of nursing facilities told us about their daily lives, they often described a world characterized by impersonal regimentation and segregation from the broader community. One 53-year-old woman expressed frustration over the presence of “so many rules” in the nursing facility and remarked, “I’m old enough to be free.” A 78-year-old resident said she missed “everything” about home and added, “I miss being able to go outside by myself. Here, if you don’t have someone to take you, you can’t go.” A 74-year-old Native American resident similarly reported that the nursing facility feels like “a prison” because he cannot go outside without getting “in trouble.” He said that one time, he walked off the premises to buy cigarettes at a nearby gas station and the nursing facility called the Sheriff, who came and took him into custody. He was frightened by the experience; and when he returned, nursing facility staff members threatened to call the Sheriff again if he tried to leave. When asked about the incident, the Director of Nursing explained that whenever any resident leaves without permission, the person is considered an elopement risk and must thereafter be accompanied if they leave the building.

A number of residents reported that nursing facility staff members prohibited them from completing physical tasks, even when they were capable of doing them on their own. One 55-year-old resident said he is aware that he needs assistance with some activities but wants to maintain as much independence as possible. He added, “I’m not a person if I don’t try.” But he said that the nursing facility staff did not allow him to do things on his own, so he has been unable to learn to do things independently. For example, he told us that if he were to return home, he was no longer sure he could cook for himself, because the nursing facility staff would not even allow him to open a can of vegetables on his own. Another nursing facility resident, who is 78 years old, said nursing facility staff members prohibit her from even trying to get out of bed or putting on her own shoes. This kind of induced helplessness is an all-too-common result of institutionalization and hinders residents’ ability to transition back to their homes with the skills necessary to be as independent as possible.

Most nursing facilities offer residents activities, but they are usually group activities planned with little regard to individuals’ interests. Activities we observed repeatedly included video sing-a-longs, bingo, arts and crafts, puzzles, television watching, or board games. Residents report feeling bored in nursing facilities, and they frequently spend time alone in their rooms. As one 73-year-old woman explained, “I just kinda sit here.” Many residents report missing their pets, however, few facilities allow residents to have them. Some residents choose to smoke cigarettes outside to pass the time; however, smoking is a highly regulated and restricted activity in nursing facilities. If smoking is allowed, residents are often required to obtain their cigarettes from a dedicated employee who maintains control over the residents’ cigarettes and only distributes cigarettes at certain intervals of the day. And if alcohol is

permitted at all, residents who wish to drink alcohol are restricted to limited and doctor-prescribed amounts and must go to a nurse to obtain it. Restrictions on these types of personal lifestyle choices are rarely based on medical needs.

A number of individuals in these facilities have families who visit and offer as much support as they can. But many families live far from the institutions and, for that reason, it is difficult to visit regularly. Other individuals do not have family who are involved in their lives or who can offer support. For those individuals, interaction with individuals who do not have disabilities is often limited to infrequent organized trips to nearby restaurants or local attractions, many of which are not age-appropriate or responsive to the residents' interests. For example, one nursing facility administrator said staff members occasionally take residents to a local children's theme park; another facility reported taking residents for rides in the country to look at the farms where they used to live. The outings offered by nursing facilities do little to engage residents with their communities because they are infrequent and almost always require residents to travel together.

Given these and other characteristics, nursing facilities are institutional, segregated settings that, through their restrictive practices and control over individualization and independence, limit a person's ability to interact with other people who do not have disabilities.

## **B. Nursing Home Residents in South Dakota Want to Live in and Can Be Served in Their Own Homes and Communities**

*"I always had my own place. I just want to be alone. I want out of here soon so I could have privacy to leave when I want, cook when I want." – Nursing Facility Resident*

States have an obligation to provide services in community-based settings where such placement is appropriate for and not opposed by persons with disabilities. *Olmstead*, 527 U.S. at 607. As explained below, the vast majority of individuals with disabilities in South Dakota nursing facilities could be served in integrated settings. The placement of people with disabilities in nursing facilities in South Dakota is not based on a determination that the person cannot be served in the community. Rather, people with disabilities tend to enter nursing facilities simply because there are not services available in their communities or because they and their families are not aware of services that exist or are unable to access them. Moreover, many of these individuals want to live in their own homes.

### **1. Individuals with Disabilities in Nursing Facilities Can Be Served in Integrated Settings**

The great majority of individuals in South Dakota's nursing facilities can be served in the community with appropriate supports. Many of the individuals in South Dakota's nursing facilities have chronic health conditions, such as diabetes, or physical disabilities, such as blindness or other visual impairments, amputations, or mobility limitations. We also met individuals with multiple sclerosis, muscular dystrophy, severe arthritis, intellectual and developmental disabilities, brain injuries, and mental illnesses. Most of these individuals are living in nursing facilities because they need assistance with activities of daily living or instrumental activities of daily living due to these disabilities and health conditions. They may require assistance with tasks such as dressing, preparing meals, medication management, using

the toilet, or handling financial affairs, among others. Many also require some health care services, like nursing care, or rehabilitative services, such as physical therapy. But with access to these types of services in the community, the same individuals could receive the assistance they need to live in their own homes, instead of nursing facilities.

After visiting nursing facilities across the State with an expert, interviewing numerous residents, and reviewing care plans, we found that the residents we interviewed could live in the community with appropriate supports. Many people would need no more than a few hours each day of personal care assistance with tasks such as bathing, shopping, preparing meals, grooming, and medication management; occasional in-home nursing visits; and some homemaking assistance. Many others primarily need services due to severe vision impairments or assistance managing diabetes. We encountered some residents who periodically leave the nursing facilities for days at a time to visit family or spend time with friends, which indicates that they could be served in the community on a continual basis.<sup>9</sup> Our expert concluded that the types of services and supports that exist in South Dakota's community service system, if expanded, could meet the needs of most nursing facility residents with disabilities whom we met. For example, one 77-year-old man with diabetes lost his vision and went to a nursing facility after a toe amputation. He recognized the need to check his feet regularly, but needed help with this because he could not see. He was unable to find any help in the community and had no family support. He wanted to move out of the nursing facility and needed only minimal assistance to live at home. When we met him, he had been living in the nursing facility for over five years.

As part of our investigation, we asked the State to identify all of the Medicaid-eligible nursing facility residents who could be served in an integrated setting. The State identified 12 residents. Our expert met with and reviewed records of several of these residents. She concluded that these individuals' needs were not materially different than the needs of the majority of the individuals we met in nursing facilities across South Dakota, suggesting that, by the State's own assessment, many more individuals are able to be served in an integrated setting.

Nursing facility administrators acknowledged that if the appropriate resources were in place to support individuals in the community, they could send a substantial number of people home. Directors of nursing at many facilities identified numerous residents they thought could live independently with the right services. Similarly, community providers reported that with appropriate services and supports, many individuals in nursing facilities could live at home.

Without access to needed assistance in the community, however, many people and their families believe that a nursing facility is the only place to get care. A State-commissioned assessment of South Dakota's long-term care system explained that "[a] relative abundance of nursing home beds, coupled with the lack of home and community based alternatives" tends to cause "less disabled elders [to] enter nursing homes for care."<sup>10</sup> The State's efforts since this study was issued in 2007 have not significantly increased the availability of services that can support individuals in their homes.

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<sup>9</sup> Some of these individuals wanted to be home for even more time, but Medicaid rules require that no resident be out of the nursing facility for non-medical reasons for more than 15 consecutive days. S.D. Admin. R. 67:45:02:04.

<sup>10</sup> Abt Associates, Inc., *Evaluation of Long-Term Care Options for South Dakota* 31-32 (2007) ("Abt 2007 Report").

A 2014 AARP report confirmed that more of South Dakota's nursing facility residents have low-care needs than nursing facility residents of other states. In the five best performing states, 4.6% of nursing facility residents had low-care needs, while 16.7% of South Dakota's nursing facility residents have low-care needs.<sup>11</sup> Another national report found that individuals in South Dakota's nursing facilities have the fourth lowest need for assistance with certain activities of daily living among states.<sup>12</sup> This suggests that many of the individuals in South Dakota nursing facilities are able to live in the community with appropriate, and perhaps minimal, supports.

Some people in nursing facilities may require a greater amount or intensity of services than those with low-care needs, but these individuals too can and should receive services in community settings. These individuals may require regular supervision or supports, whether due to physical or cognitive disabilities or other chronic illnesses, although few require 24-hour hands-on care. For example, other states serve people with severe dementia in the community by offering host homes in which individuals can choose to live with a paid family member or professional caregiver; small group homes; or 24-hour in-home supervision. These settings allow people with dementia to receive individualized care, and restrictions can be limited to only those that are related to a medical or safety need. When their needs are addressed in an individualized manner, people with dementia often have better outcomes and fewer challenges interacting with their surroundings. Similarly, in other states individuals with mobility limitations who need assistance transferring or using the toilet at unplanned intervals are served in integrated settings with a sufficient number of personal care hours, or with on-call assistance.

There are also people with the same needs, diagnoses, and symptoms as nursing facility residents who live successfully in the community in South Dakota, either through the State's waiver programs or by paying privately for services. This group includes individuals with low-care needs as well as those who have more complex medical needs and those who need regular supervision and support. Several community providers reported that they can serve individuals who need as many as 24 hours of care each day in the community, and they already do so for individuals who can pay privately for services. Indeed, community providers are currently serving individuals with higher needs and who may require more intensive community services, including those with Alzheimer's disease, dementia, and brain injuries. Furthermore, the State already supports thousands of people with intellectual and developmental disabilities in the community through Medicaid waiver programs. These individuals have similar needs to many people in nursing facilities who have developed or acquired cognitive disabilities.

Our expert concluded that the needs of people who live in South Dakota's nursing facilities are not materially different than the needs of people with disabilities who live successfully in their own homes and communities in other states across the country. In other states, thousands of people are able to stay in their own homes and participate in their

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<sup>11</sup> Susan C. Reinhard et al., AARP, *Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities and Family Caregivers* 14, 88 (2014) ("Raising Expectations").

<sup>12</sup> Charlene Harrington et al., Kaiser Commission on Medicaid and the Uninsured, *Nursing Facilities, Staffing, Residents and Facility Deficiencies, 2009 Through 2014* 34 (2015), <http://files.kff.org/attachment/report-nursing-facilities-staffing-residents-and-facility-deficiencies-2009-through-2014>.

communities with appropriate community supports, including the types of supports that already exist in South Dakota, rather than having to enter a nursing facility. The people living in South Dakota's nursing facilities are no different.

2. Nursing Facility Residents with Mental Illnesses, Intellectual and Developmental Disabilities, and Brain Injuries Can Be Served in the Community

Many individuals are segregated in South Dakota's nursing facilities because they require care or assistance due to mental illnesses, intellectual and developmental disabilities, and traumatic brain injuries. Some of these people are further segregated based on their specific disability in designated nursing facilities or units. Many of these individuals can receive services in integrated settings.

For example, in 2008, the Department of Social Services, in conjunction with a private nursing facility, opened a nursing facility unit in Irene, South Dakota, to provide specialized care for individuals with traumatic brain injuries. This traumatic brain injury unit was created to allow several South Dakotans to return home to the State, having previously only been able to access adequate care elsewhere. But the State has not developed alternative, community-based services for South Dakotans who require services due to traumatic brain injuries. Rather, it has cut services that once existed and has declined to pursue federal funding that could help create a home- and community-based services program for people with brain injuries. Instead, the State funds the placement of approximately 80 people with traumatic brain injuries in the Irene facility and other nursing facilities across South Dakota.

Individuals with mental illnesses are also needlessly institutionalized in nursing facilities. More than 21% of Medicaid-funded nursing facility residents in South Dakota have indications of a serious mental illness, including diagnoses of schizophrenia, bipolar affective disorder, and psychotic disorders. Serious mental illness contributes to the placement of many individuals in nursing facilities, and these individuals are unable to transition to the community without sufficient community-based mental health services. One assisted living administrator noted that when residents exhibit a need for intensive mental health services, they have to move to nursing facilities; another confirmed that when they have to ask residents to leave assisted living due to "bad behavior," they probably go to nursing facilities.

Mental health needs can create added barriers for individuals who wish to leave nursing facilities when services are unavailable to meet those needs in the community. One resident who entered the nursing facility due to an amputation reported he was staying at the facility simply because he wanted to be somewhere he could get regular counseling to learn to manage a prior trauma. He is also diagnosed with anxiety and depressive disorder, and his care plan indicates that he has behavioral needs. He did not know whether it was possible to get counseling in his home but said he would want to leave the nursing facility if that were possible.

Lack of appropriate substance use services in the community further contributes to this problem. Nursing facility administrators told us of several people who they thought needed to be in the nursing facility primarily due to alcoholism. One man told us he didn't bother to ask to go home, knowing he would be told, "No, you're going to be drinking." He added, "I can damn well live on my own, but just one drunk episode and they write you off." When asked about the man, the director of nursing at his facility confirmed that he was primarily in the nursing facility

to address his alcoholism, and had cycled in and out of the facility for this reason, but he would otherwise “be fine on his own.”

South Dakota does offer some of the necessary community-based mental health services for people with mental illness, including Assertive Community Treatment teams and mobile crisis services,<sup>13</sup> as well as some limited services for people with substance use disorders. But these services are sparse and are not sufficiently reaching people who need them. In other states that offer appropriate community-based supports, individuals who have mental illness or substance use disorders are served successfully in the community.

We also met individuals with intellectual and developmental disabilities living in nursing facilities who had not been able to access appropriate community-based services. Across South Dakota, approximately 190 such individuals live in nursing facilities funded by the State. One man we met had moved to the nursing facility from a group home in the community. He told us he wanted to live in the group home again someday, but had nobody to help him move.

South Dakota has an array of services for individuals with intellectual and developmental disabilities, and the State already supports many such individuals in the community. South Dakota’s Family Support 360 and CHOICES waiver programs provide at-home supports for individuals of any age who have an intellectual or developmental disability if they meet the level of care for an Intermediate Care Facility. Individuals with intellectual and developmental disabilities can use these services to live in integrated community settings, but the State must ensure that they can access such services.

### 3. Nursing Facility Residents Want to Live in Community Settings

South Dakotans with disabilities, and their families, want alternatives to segregated, institutional nursing facilities. The State recognized in its 2009-2013 State Plan on Aging that “South Dakotans overwhelmingly indicate they prefer to age in place within their own homes and communities.”<sup>14</sup> A report commissioned by the State also acknowledged that there is a “growing desire among elders to remain in their own homes and independent for as long as possible,” and that national studies similarly reveal a preference among older adults for services that allow them to age at home.<sup>15</sup> Indeed, as the State has explained, “[m]ore and more individuals who are older are asking to stay in their homes and communities as long as possible

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<sup>13</sup> Assertive Community Treatment is a team-based treatment model that provides multidisciplinary, flexible treatment and support to people with mental illness to increase integration and prevent hospitalizations. Substance Abuse and Mental Health Services Administration, *Assertive Community Treatment: Building Your Program 5*, Pub. No. SMA-08-4344 (2008). Mobile crisis services provide rapid response to assist and stabilize individuals in the community who are experiencing a psychiatric emergency, allowing individuals to avoid hospitalization and police contact. Substance Abuse and Mental Health Services Administration, *Crisis Services: Effectiveness, Cost-Effectiveness, and Funding Strategies 10*, Pub. No. SMA 14-4848 (2014).

<sup>14</sup> S.D. Dep’t of Social Servs., *South Dakota State Plan on Aging, October 1, 2009 – September 30, 2013 3* (2009) (“2009 State Plan on Aging”).

<sup>15</sup> Abt 2007 Report at 2.

while receiving the necessary support services such as home health, homemaker, respite care, nutrition, adult day services, transportation and others.”<sup>16</sup>

In 2002, an AARP survey in South Dakota found that half of those surveyed considered it “very important” to live and receive care in their own homes for as long as possible.<sup>17</sup> And in 2012, in response to another AARP survey, 73% of South Dakotans age 50 or older living in small towns and rural areas said it was extremely or very important for them to remain in their community or area for as long as possible.<sup>18</sup> Of this same cohort, 65% felt expanding access to home- and community-based long-term care services should be either a top or high priority in the State.<sup>19</sup> Twenty-six percent reported that home health or visiting nurse services were unavailable in their community, and another 14% did not know whether such services were available.<sup>20</sup>

National reports also recognize a widespread preference among people with disabilities of all ages to receive assistance in their own homes and communities. For example, AARP’s national survey of adults age 45 and older revealed that over three-quarters of those surveyed strongly preferred to remain in their current residences as long as possible. Older respondents were the most likely to strongly agree with this statement.<sup>21</sup>

Our investigation similarly revealed that a significant number of individuals in South Dakota nursing facilities have a clear preference for living at home or were open to the idea of transitioning to the community if their concerns were addressed about appropriate services. For example, one 67-year-old resident told us he very much wants to move to his own place because he will “never be happy” in the nursing facility. Another resident, who was 47, told us that he missed having the freedom to come and go as he pleases. He added, “Now all I want to do is find someone and put down roots. I’m not going to be able to do that in here.” Another said, “I’m not thrilled to be here. I didn’t want to be here. I want to go home.” One woman told us, “I don’t know if [my husband and I] could go home, but I would sure like to. We would have to get someone to come in a few times a day.”

A 73-year-old man who uses a wheelchair for mobility due to a car accident earlier in life told us he was in the nursing facility against his “own free will,” and added “some of these places are warehouses.” He explained that his parents, who are in their nineties, lived in another part of the State. Because he cannot leave the nursing facility to visit them, he is afraid he will not be able to see them again before they die. He added that he fears he will live as long as his parents and that he will be “stuck” in the nursing facility until he dies.

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<sup>16</sup> S.D. Dep’t of Social Servs., *Meeting the Continuum of Care Needs of the Elderly in South Dakota Task Force: Report 6* (2008).

<sup>17</sup> Abt 2007 Report 2 (citing Mildred DePallo & Anita Sowell-Ritter, AARP, *South Dakota Long-Term Care: An AARP Survey* (2002)).

<sup>18</sup> AARP, *Experience and Opinion of Older Rural South Dakotans about Transportation: An AARP Survey 6* (2012).

<sup>19</sup> *Id.* at 17.

<sup>20</sup> *Id.* at 10.

<sup>21</sup> Teresa A. Keenan, AARP, *Home and Community Preferences of the 45+ Population 1* (2010), <http://assets.aarp.org/rgcenter/general/home-community-services-10.pdf>; see also Mia Oberlink, *Community Innovations for Aging in Place (CIAIP) Final Report 2-3* (2014).

Though many nursing facility residents are older, this population is not limited to older adults, and there are a number of younger, working-age residents unnecessarily institutionalized in nursing facilities who also want to move to the community. For example, one 47-year-old man with quadriplegia had been in the nursing facility for three years when we met him. He was eager to get a job and return to the community, where he had successfully lived before, but he acknowledged that he would need assistance if he did so. A 45-year-old resident with diabetes explained that although he wanted to return home to his wife and teenage daughter, he needed home modifications to help him move about the house with one leg. A 51-year-old woman we met, whose multiple sclerosis manifested after she gave birth to her daughter at age 29, was left by her husband at the hospital after he could no longer care for her and their home. The hospital transferred her to the nursing facility, and she had been living there for nearly three years when we met her. She told us she misses being home with her dog and her daughter, and wishes she could go to the mall and have her own bedroom.

Individuals with disabilities living in the community also express a strong desire to avoid nursing facility admissions and stay in the community as long as possible. Many of these individuals had previously lived in a nursing facility or other institution and, based on that experience, hoped never to return. For example, a 52-year-old woman with quadriplegia who maintains limited use of one hand told us she will “do whatever is necessary to stay at home” and avoid returning to the nursing facility, where she lived unhappily for several years before returning home with the help of a community advocate. Another woman, who is 67 years old and receives waiver services, is only able to remain in her home with the added help of a friend, who volunteers every day to do housekeeping chores. The woman said she “would rather be dead” than return to the nursing facility, which she described as a miserable experience. Another waiver recipient, who fears she is not receiving enough care to remain in the community and who previously lived in a nursing facility for approximately one month following an amputation, reported that it “sucks” and that she did not want to return. Nursing facility administrators also observed that people want to stay at home as long as possible, even when they do not have appropriate care. As a result, they often see people who come in for care after deteriorating at home due to a lack of services.

We also spoke with many family members who faced the difficult decision of whether to place their loved ones in nursing facilities. Many made the decision after the person’s needs became so great that they could no longer care for them alone, and they were never offered alternative community-based supports. Often, family members had to make these decisions although they knew their loved ones did not want to live in nursing facilities. Others we spoke with were still struggling to support their loved ones in the community but felt they did not have sufficient assistance. One man told us that, after his mother had a recent fall, “I might have to take my mom to a nursing facility, only because I can’t help her with a bath or dressing.” In the absence of access to sufficient home- and community-based services for their loved ones, these family members are choosing the only apparent option: nursing facility placement.

### **C. South Dakota Administers Its Long-Term Care Service System in a Way that Segregates Individuals with Disabilities in Nursing Facilities or Puts Them at Serious Risk of Nursing Facility Placement**

*“If I’d got just a little bit of support, I could have gone home. If I could see, I wouldn’t have to be here.” – Nursing Facility Resident*

Due to the State’s policies and practices, nursing facilities are the only service setting available to many South Dakotans with disabilities, even though such facilities are not the most integrated setting appropriate. Although South Dakota offers an array of community-based services, the State has not developed these services in sufficient capacity or effectiveness to meet the needs of unnecessarily institutionalized persons and those at serious risk of unnecessary institutionalization. Instead, the State has disproportionately directed its resources toward institutional nursing facility services.

As the State has acknowledged, “adequate home and community-based services are instrumental to reducing nursing home utilization.”<sup>22</sup> Recent reports commissioned by the State similarly explained that “[h]ome and community based services are a critical support component to allow elders to remain in the community as long as possible” and “fulfill their desire to remain independent and in their homes.”<sup>23</sup> This is true for all individuals with disabilities who require assistance with day-to-day activities.

#### **1. South Dakota Unnecessarily Relies on Institutional Settings to Serve Individuals with Disabilities**

##### *i. South Dakota Disproportionately Funds Institutional Services Instead of Developing Sufficient Home- and Community-Based Care for People with Disabilities*

The State has opted to invest an overwhelming portion of its Medicaid long-term care dollars in nursing facilities, instead of community-based services. In fiscal year 2013, South Dakota spent \$132,970,013 in Medicaid funds on nursing facility care. Yet the State spent just \$26,641,301 on home- and community-based services for older adults and people with physical disabilities receiving Medicaid services. Put another way, just 16.7% of South Dakota’s spending on long-term services and supports primarily for older adults and people with physical disabilities goes toward community-based services. Even including State funding for people who are not eligible for Medicaid, only about 20% of South Dakota’s total long-term services and supports budget for older adults and people with physical disabilities goes to community-based services. South Dakota is far below the national average in this regard. On average, 40.2% of states’ Medicaid spending on long-term care for older adults and people with physical disabilities goes toward community-based services, and this figure does not include states’

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<sup>22</sup> 2009 State Plan on Aging at 2.

<sup>23</sup> Abt Associates, Inc., *Evaluating Long-Term Care Options for South Dakota: Update 39* (2015) (“Abt 2015 Report”); Abt 2007 Report at 1.

spending for individuals not eligible for Medicaid. Indeed, the State has acknowledged that it “spend[s] a disproportionate percentage of Medicaid resources on institutional care.”<sup>24</sup>

The State has also acknowledged that home- and community-based services are insufficient, but it has taken few steps to expand these services. South Dakota commissioned Abt Associates to evaluate the State’s long-term care system in 2007 and commissioned an updated report in 2015. Abt’s 2007 report found that increasing numbers of older adults prefer home- and community-based services, and found low utilization and availability of such services in the State. Abt found that “[c]urrent care patterns are far from national norms: South Dakota has one of the highest rates of nursing home use by seniors in the country, but lags in utilization of skilled health care services and home and community based services.”<sup>25</sup> Abt concluded that “[l]ow rates of [home health care] utilization are likely due to lack of available providers, access problems and practice patterns that discourage use of services.”<sup>26</sup> With respect to home health services, Abt found that “available services would have to increase by [more than] 300% statewide” in order to reach national averages of home health use.<sup>27</sup> Abt’s 2015 report found little evidence of expansion in the provision of home- and community-based services and concluded that the State “continue[d] to lag behind national averages” in this regard. The 2015 report concluded that “aggressive rebalancing efforts will be required to support increasing numbers of community-dwelling seniors in the future.”<sup>28</sup>

South Dakota’s 2009-2013 State Plan on Aging also recognized the State’s significant reliance on institutional care and called for a drastic increase in community-based services. The 2009-2013 Plan concluded that “[w]hile South Dakota has a high rate of nursing home bed use, the state ranks the second lowest in the country in terms of use of skilled home health services . . . . The state must double home health service capacity immediately and increase capacity 3-4 fold by 2025 to meet expected population growth and move toward the national norm for home health use . . . .”<sup>29</sup> South Dakota’s current State Plan on Aging for 2013 to 2017 suggests there has been little improvement.<sup>30</sup>

South Dakota’s delay in implementing measures to address unnecessary institutionalization leaves thousands of people without critical community services that are necessary to avoid nursing facility admission and long-term placement. South Dakota has long studied the issues existing in its long-term care service system, and it has begun to make some efforts to address these challenges, but those minimal efforts have produced few results to date. Following the release of the first Abt report, South Dakota convened several task forces and working groups to examine services for people with disabilities. These groups made several

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<sup>24</sup> S.D., Office of the Governor, *Medicaid Solutions Work Group: Recommendations to Contain Costs within South Dakota’s Medicaid Program* 15 (2011).

<sup>25</sup> Abt 2007 Report at 29.

<sup>26</sup> *Id.* at 39.

<sup>27</sup> *Id.* at 66.

<sup>28</sup> Abt 2015 Report at viii.

<sup>29</sup> 2009 State Plan on Aging at 1.

<sup>30</sup> S.D. Dep’t of Social Servs., *South Dakota State Plan on Aging, October 1, 2013 - September 30, 2017* 1-3 (2013).

recommendations, but they appear to have had little impact on people’s access to community-based care. Indeed, in its second report, Abt found no evidence of increased availability of home- and community-based services from 2007 to 2015.<sup>31</sup>

In 2008, the Department of Social Services convened a task force to assess and evaluate South Dakota’s long-term care system for older adults. That task force issued a report in November 2008 acknowledging “the general lack of home and community-based care available in the state,” and proposed a number of recommendations for the State to address this issue.<sup>32</sup> In 2011, the State established a Medicaid Solutions Work Group to develop strategies to control Medicaid costs, including a Home- and Community-Based Services Subcommittee. In its final report, the Work Group recognized that “[o]ver-reliance on institutional care” contributed to increased Medicaid costs, and it “[e]ncourage[d] the appropriate utilization of less costly home- and community-based services.”<sup>33</sup>

In response to these groups’ recommendations, South Dakota has taken some steps to expand access to home- and community-based services. The State has added some limited services to the Home Services Waiver and has created the Aging and Disability Resource Connections program. The State has begun implementing Money Follows the Person and had successfully transitioned just 10 people out of nursing facilities as of April 2015, but the program could be a useful framework for a successful transition program if effectively implemented. The State also elected to pilot a shared living program, which appears to be designed to improve on its existing host home model. Yet, as discussed below, each of these programs is far from reaching its full potential in enabling individuals to access appropriate services. And it appears few, if any, additional steps have been taken to expand home- and community-based services in the State.

In 2013, the State also formed a Dementia Care Work Group to examine the services available to adults with dementia-related conditions. The group did not consider ways the State could develop dementia-competent home- and community-based services that would allow individuals to receive care in their own homes. Instead, the group focused solely on expanding assisted living facility access. And most recently, the State has established a Home- and Community-Based Services Task Force, which began meeting in May 2015 to discuss the availability of community services and the obstacles to South Dakotans receiving community services. We applaud the State for taking these initiatives and for placing emphasis on involving stakeholders in the process. However, at this point, the real impact of these efforts has been limited, and study has taken the place of actual expansion of services.

Finally, the State does not have an enumerated *Olmstead* plan that lays out how it plans to serve people with disabilities in the most integrated settings. Instead, an array of statutes, administrative rules, policies, and procedures govern South Dakota’s disability service system. The State’s failure to redirect resources and its failure to prioritize home-based services over

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<sup>31</sup> Abt 2015 Report at vi, 39.

<sup>32</sup> S.D. Dep’t of Social Servs., *Meeting the Continuum of Care Needs of the Elderly in South Dakota Task Force: Report 1* (2008).

<sup>33</sup> S.D., Office of the Governor, *Medicaid Solutions Work Group: Recommendations to Contain Costs within South Dakota’s Medicaid Program: Final Report 3*, 15 (2011).

institutional nursing facility care has confined thousands of people with disabilities unnecessarily and indefinitely in nursing facilities and puts many others at serious risk of unnecessary institutionalization.

*ii. South Dakota's Extensive Investment in Assisted Living Facilities has Limited Access to Integrated Community Services*

South Dakota's extensive use of institutional assisted living facilities has further limited the services available to support individuals in integrated settings, including their own homes. While South Dakota has slightly reduced nursing facility use over the past several years, this reduction has largely been accounted for by an increase in assisted living use and not by more integrated service options. The State's assisted living capacity is higher than the national average and drastically higher than service capacity available for individuals in their own homes. Indeed, 66% of South Dakota's spending on the Home Services Waiver program goes to assisted living facilities. Although some people may choose to live in assisted living facilities, assisted living facilities are frequently the only practical alternative to a nursing facility for many individuals due to the limitations on services available to people in their own homes. As a result, of the roughly 1,200 people who receive services under the Home Services Waiver program at any given time, only 36% are actually being supported to live in their own homes.

Many of the assisted living facilities in South Dakota<sup>34</sup> are segregated and institutional in many of the same ways as nursing facilities in the State, and for a number of individuals with disabilities, assisted living facilities are not the most integrated setting appropriate to their needs. Assisted living facilities are often difficult to distinguish from nursing facilities. This is due, in part, to the institutional nature of the physical environment, which tends to isolate residents from the greater community because it is designed specifically for people with disabilities. South Dakota's assisted living facilities range in size up to 140 beds. Many have long corridors, common areas that resemble hospital lobbies, and shared bedrooms that are similar in size to those found in nursing facilities. Some assisted living facilities deliver medications on a cart and have restricted areas where residents are not permitted. Furthermore, residents have little opportunity to interact with the broader community or people who do not have disabilities, other than paid staff. Instead, like nursing facilities, many assisted living facilities are designed to provide multiple types of services and activities on-site, including nursing care, housing, and social activities, and in almost all of the assisted living facilities we visited, the facility is the sole provider of all waiver services for residents. Moreover, some assisted living facility beds are located in the same building as nursing facilities, yet these facilities receive Medicaid funding for home- and community-based waiver services.

The institutional nature of assisted living facilities is further amplified by the fact that residents often live under similar restrictions as they would if they were confined to a nursing facility. Depending upon the assisted living facility, some of those restrictions include prohibitions on residents' ability to come and go, regimented meal and bathing times, assigned seating in meal areas, lack of choice as to roommates, prohibitions on keeping pets, and little to no access to kitchens. For example, one woman who lives at an assisted living facility told us

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<sup>34</sup> There is no nationally accepted definition of assisted living, and such facilities may vary from state to state. For purposes of this letter, we are referring only to the assisted living facilities in South Dakota.

she wished she had access to a kitchen so she could cook and bake for herself. In the assisted living facility, all she could do was ask an aide to melt marshmallows in the microwave so she could make Rice Krispies treats. Her neighbor also had to walk through her room in order to use the bathroom. This example and many others are indicative of the fact that at most South Dakota assisted living facilities, residents do not live in a setting that is integrated in the community; they live in a segregated, regimented setting that, for the most part, provides services for people with disabilities.

Similar to nursing facility residents, many individuals in assisted living facilities want to live in their own homes. For example, one assisted living resident said he “hate[d] being penned up” in the facility and wished to “be free.” Yet individuals with Medicaid who enter assisted living facilities generally do not move back home. As one assisted living facility administrator told us, “everyone here knows they can’t go home.” In one assisted living facility that served primarily adult men with mental illness, the administrator said he wished there were a way for the Medicaid funding to “follow the person” to an integrated setting, noting that the residents in that facility often just need medication assistance and help managing their money, along with a safe, accessible place to live. In other words, the administrator acknowledged that his residents could live at home if they could be connected with relatively minimal community services and affordable housing.

People who need long-term services and supports must have the opportunity to choose to receive this care in integrated settings. Rather than living in 24-hour facilities, many individuals with disabilities want to live in their own home or apartment – either alone, with family, or with roommates of their choosing – where they can receive services in the amount and intensity they need. For others, residential services that provide individuals with 24-hour supervision or assistance may be preferable. This may include, for example, supported apartments that allow individuals to live in their own homes with access to on-site assistance and services, small assisted living facilities that provide independent apartments, or host homes that allow individuals to be matched with an appropriate host to provide basic, regular assistance. Indeed, the State’s existing host home model could be expanded to provide some of these services. In any event, any residential setting must be the most integrated setting appropriate for the individual and provide support for individuals to access community activities and interact with individuals without disabilities to the fullest extent possible. Individuals must also have the option to receive necessary services and supports in their own homes. The assisted living facilities in South Dakota that we visited generally do not provide for community integration, and the lack of in-home service availability impedes individuals’ ability to access the most integrated setting appropriate to their needs.

South Dakota’s extensive funding of institutional assisted living facilities and comparatively restricted funding of cost-effective services in individuals’ own homes or other integrated residential service models has further exacerbated the shortage of integrated, community-based services and has pushed individuals from their homes to segregated living facilities.

## 2. South Dakota Does Not Adequately Identify and Transition Individuals in Nursing Facilities to Home- and Community-Based Services

Thousands of people with disabilities in South Dakota, often with the help of family members, have already sought long-term care and found themselves in a nursing facility because they were unable to identify or arrange sufficient community options. Many of these people have lived in nursing facilities for years and, if the current trend continues, will do so for the years or decades until they die. For those who have lived in a nursing facility, moving back home can be an increasingly challenging process. Many individuals and their families do not know that they can choose to receive services in the community or that services exist that could meet their needs; few know where to begin or whom to ask for assistance moving home. For those who move to the community, needed services and supports, like daily assistance, housing, and transportation, must be planned and arranged in an efficient and coordinated fashion. An effective transition system that addresses these challenges is thus essential to ensure that individuals living in nursing facilities can move back to the community when they choose. Such a system must regularly provide nursing facility residents with information about available community services, identify nursing facility residents who are appropriate for and do not oppose transition, and provide case management and transition planning to help individuals identify and arrange needed services in the community. But the State does not have such a system.

The State does not sufficiently identify nursing facility residents for potential transition, educate and inform residents about alternative services, or provide residents assistance arranging services to enable them to transition back to their communities. In 2009, South Dakota transitioned to the community only 5.2% of individuals with nursing facility stays over 90 days. South Dakota ranked 49th in the nation in this regard.<sup>35</sup> As the State expands services, it must ensure that it has an effective mechanism to help individuals living in nursing facilities learn about community options, make informed decisions about the services they want and need, and transition safely to community settings.

Nursing facility residents who are able to live at home – and their families – are generally unaware that there are public programs that allow people to receive assistance in the community. One 86-year-old woman explained that although she is physically capable of living at home with assistance, “that’s not possible because it costs [money].” Residents consistently reported that no one had ever spoken to them about leaving the nursing facility. Many residents had the impression that they should not bother asking for assistance with leaving, because they would be told they could not leave. A 51-year-old Native American man we met had been living in a nursing facility for over a year following an amputation of one of his legs. He was desperate to return to his hometown, but he believed that nobody at the nursing facility would help him get out. He wept as he told us he had been trying to leave for months, but thought staff had given up on him. Yet he would likely only need two to three hours of assistance twice a week, a prosthesis, and assistance re-learning how to manage his diabetes.

The federal government awarded South Dakota the Money Follows the Person grant in October 2012, and the State began implementing the program in May 2013 to identify and support individuals who wish to transition to the community. Yet few individuals appear to be

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<sup>35</sup> *Raising Expectations* at 89.

benefitting from this program, and some nursing facility administrators had not even heard of it. The State initially fell short of its original transition goals for older adults and individuals with physical disabilities and has had to revise these goals downward. South Dakota did not achieve any transitions through Money Follows the Person during 2013. In 2014 and the first quarter of 2015, the State transferred three individuals older than 65 and eight younger people with physical disabilities to the community from nursing facilities; one of these individuals returned to the nursing facility. As currently operated, this program has not resulted in an effective, state-wide system for assisting individuals with disabilities in nursing facilities to transition to the community. The State did not apply for the Money Follows the Person Tribal Initiative, which is specifically designed to help tribes develop community-based long-term care supports, and therefore missed an opportunity to bring much needed services to the State's Native American population.

In the absence of a State system to identify nursing facility residents who are appropriate for community placement and help them plan for transition back to the community, South Dakota inappropriately relies on nursing facilities for these roles. Nursing facilities are not community-based providers, have little experience and understanding of the services and supports necessary for individuals to live in the community, and have little incentive to transition individuals from their facilities.

For example, South Dakota nursing facility staff consistently and inappropriately identified individuals who are appropriate for in-home care as needing to remain in the facility. Administrators and residents' care plans indicated people could not leave "because they can't do their own [activities of daily living]," such as maintaining hygiene, preparing meals, or managing financial matters, yet these are common needs that can be met effectively in the community. Indeed, the State's service system includes personal care services that can assist individuals in their homes with these very tasks. Other nursing facility staff thought that individuals who required a mechanical lift to transfer, who needed multiple care providers, or who did not have any family were categorically unable to live at home. Other reasons for institutionalization cited by nursing facilities included needing to lose weight and needing help remembering to see a doctor. None of these needs or characteristics would be a barrier to living at home if appropriate and sufficient services were provided. Similarly, nursing facility staff often stood in the way of transition assistance. One administrator admitted that if a resident asked to leave, staff members would try to convince the person why they could not leave. Another said staff would wait for the resident to raise the issue of moving home, even if it was clear the person could live at home.

According to the State, it uses individuals' responses to Section Q of the Minimum Data Set<sup>36</sup> to make referrals to community-based living from nursing facilities. But for almost half of the individuals we met, recorded answers indicating no interest in returning to the community

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<sup>36</sup> Section Q is a section of the federally-mandated Minimum Data Set, which is a comprehensive assessment of residents' functional capabilities and needs that all Medicaid-certified nursing facilities must complete. Section Q requires that residents be asked if they wish to speak to someone about returning to the community. The Minimum Data Set also allows states to introduce optional questions to gather data points not otherwise included in the assessment. Nursing facilities are responsible for administering this assessment on a regular basis. The State can examine Minimum Data Set data to identify individuals with particular characteristics that may suggest they are appropriate for and do not oppose community placement, including individuals who respond positively to Section Q's inquiry about community living.

were inaccurate and in stark contrast to what those individuals told us. And many individuals who did have a documented interest in community living had never been informed about services. The State can use Section Q and other Minimum Data Set information as one tool to identify individuals for transition. South Dakota must provide sufficient training and incentives to ensure that nursing facilities properly administer the assessment and the State must promptly and fully follow up with individuals who may want information about or appear otherwise appropriate for the community. And, while Section Q and the Minimum Data Set can be helpful tools to assist states in identifying individuals who do not oppose transition and are appropriate for community placement, they should not be relied upon as the sole mechanism for determining individuals' interest in transitioning to the community. The State must have a system to identify individuals for transition that is independent of nursing facilities.

Additionally, South Dakota is not conducting effective transition planning, resulting in readmissions to nursing facilities. When individuals do transition to the community, the State does not always arrange for appropriate services and supports, including the important choice of housing and residential services, consistent with individuals' needs and preferences. Nor does the State ensure that in-home service providers are involved in the transition planning process. This can put individuals at serious risk for returning to a nursing facility and can result in placement in settings that are not the most integrated settings appropriate.

Without an effective system in place to ensure that individuals living in nursing facilities can access the services they need to move back to the community, these individuals will continue to languish in facilities without any hope of returning home.

### 3. The State Does Not Adequately Divert Individuals from Unnecessary Nursing Facility Admissions or Long-Term Stays

Nursing facility stays of any significant length can result in the loss of housing and other supports that are essential for individuals with disabilities to remain in the community. Thus, a diversion program that effectively and rapidly connects individuals and their families with needed in-home services and supports after they have been referred or admitted to nursing facilities is critical to avoiding unnecessary institutionalization. For example, two important components of an effective diversion strategy include a requirement that a case worker interview every potential Medicaid-funded nursing facility resident upon referral or admission and a process for prompt approval of community services. South Dakota does not have an effective diversion system in place and fails to ensure that individuals who are referred or admitted to a nursing facility for a Medicaid stay<sup>37</sup> are offered alternative placements, both before their admission to the facility and following admission in order to avoid a long-term stay.<sup>38</sup> Instead,

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<sup>37</sup> Individuals who initially are able to pay for services using private funds often spend down their assets on long-term care until they become eligible for Medicaid. By identifying those individuals and assisting them in obtaining more affordable home- and community-based services early on, rather than expensive nursing facility stays, South Dakota may be able to both prevent unnecessary institutionalization in nursing facilities and forestall these individuals' need for Medicaid services.

<sup>38</sup> Title XIX of the Social Security Act also requires that the State offer individuals notice of and a choice between services available in institutions and in the community. 42 U.S.C. § 1396n(c)(2)(B), (C).

73% of new users of Medicaid long-term care in South Dakota first receive services in a nursing facility rather than the community, well above the national average of 46%.<sup>39</sup>

In South Dakota, 19.5% of people will stay in a nursing facility for more than 100 days, increasing the likelihood that they will never return to the community.<sup>40</sup> Nursing facility, hospital, and assisted living staff in South Dakota universally observed that individuals often move to and remain in nursing facilities because they lose their home while rehabilitating in a hospital or a nursing facility. And many nursing facility residents reported that they could not pay the rent while they were in the nursing facility and had lost their apartments, or that family members had decided to sell or give up their homes while they were in the facility. In other cases, family members made the difficult decision to encourage admission to a nursing facility after they had exhausted their ability to care for the person and had no additional supports.

South Dakota has long recognized that “[a] significant number of referrals to nursing facilities come through the hospital discharge planning process,”<sup>41</sup> but despite this recognition, the State has failed to ensure that individuals being discharged from a hospital are promptly provided necessary community-based services to avoid a nursing facility admission.<sup>42</sup> Recognizing the need to intervene during the hospital discharge planning process to ensure that individuals are provided necessary community-based services to avoid nursing facility admissions, the State’s Task Force on Meeting the Needs of the Elderly recommended adding Department of Social Services staff to hospital discharge planning teams.<sup>43</sup> Unfortunately, South Dakota has not implemented that recommendation, although some hospitals hold regular calls with Department of Social Services staff.

Nearly every resident we interviewed who came to the nursing facility from a hospital said either that no one presented an alternative to nursing facility placement or that the hospital staff had specifically recommended the nursing facility. Several said they were simply admitted to the nursing facility without any discussion. Hospital discharge workers told us they believed there were insufficient community-based services to discharge people to community settings, and some were unaware that community-based services existed. When we asked one resident why he decided to move to a nursing facility after being discharged from the hospital, he replied, “I didn’t. They decided for me. I’m not sure who actually made the decision. They just told me, ‘Hey, we’re moving you to this other facility . . . it’s a nursing facility, and you’ll have nurses there.’” Another resident told us that the hospital not only unilaterally decided to admit him to a nursing facility, the hospital also called his building management and ended his lease without his

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<sup>39</sup> *Raising Expectations* at 75.

<sup>40</sup> *Id.* at 89.

<sup>41</sup> S.D. Dep’t of Social Servs., *Meeting the Continuum of Care Needs of the Elderly in South Dakota Task Force: Report 6* (2008).

<sup>42</sup> South Dakota, through the Aging and Disability Resource Connections program, has created an optional hospital discharge planning protocol service as a guide for hospitals. However, this service is largely limited to providing information to individuals, rather than rapidly identifying and arranging for necessary community-based services to avoid a nursing facility placement. Moreover, no hospital discharge worker we spoke with articulated the existence of this process.

<sup>43</sup> S.D. Dep’t of Social Servs., *Meeting the Continuum of Care Needs of the Elderly in South Dakota Task Force: Report 6* (2008).

permission, saying he would not be coming home. His apartment was thereafter rented to someone else, and he remained in the hospital for a month while hospital staff searched for a nursing facility placement.

Regardless of the person's pathway to the facility, the State controls their entrance and continued stay, giving it the opportunity to identify and divert people to integrated settings. Medicaid-eligible individuals who are admitted to a nursing facility are screened and must be approved through the State's Medical Review Team Level of Care review process.<sup>44</sup> The State also operates the Aging and Disability Resource Connections program with the goal of providing information about available services to individuals in need. Adult Services and Aging Specialists, who screen individuals seeking long-term care services, are supposed to provide information about all service options, including home- and community-based supports, that may be available. And those already receiving public services are assigned an Adult Services and Aging Specialist who is responsible for regularly assessing changes in their needs, providing regular opportunities to inform individuals about community options and ascertain whether individuals prefer to receive long-term care services in the community. Indeed, there are, on average, approximately 1,100 Medicaid-eligible South Dakotans admitted to nursing facilities every year after receiving some Medicaid community-based services. Each one would have had contact with an Adult Services and Aging Specialist prior to admission to the nursing facility. The State could use these mechanisms to divert individuals from unnecessary nursing facility admission, but today they remain ineffective.

In the absence of an effective diversion system to rapidly connect individuals seeking long-term care to community-based services, individuals will continue to have no viable option but to enter nursing facilities and stay longer than necessary, often for the rest of their lives.

#### 4. South Dakota Fails to Address Structural Limitations that Create Barriers to Receiving Services at Home

While the State offers an array of services that are intended to support individuals in their homes and communities as alternatives to nursing facilities, limits on these services lead to unnecessary institutionalization and place individuals at serious risk of unnecessary institutionalization.

Both of South Dakota's Medicaid-funded, community-based programs for individuals with physical disabilities contain restrictions that limit their availability and effectiveness. For example, the Home Services Waiver program prohibits the hiring of relatives to provide personal care services, homemaker services, or respite services, despite the challenges program participants and providers described with finding staff, especially in rural areas. The Quadriplegia Waiver program also contains significant restrictions imposed by the State. First, it is limited to individuals with a disability that affects all four of their limbs. Participants in the Quadriplegia Waiver program are also required to "independently direct and manage" their

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<sup>44</sup> The federally-required Pre-admission Screening and Resident Review (PASRR) process also requires that all individuals who seek admission or transfer to a nursing facility be screened prior to admission, with only limited exception. See 42 U.S.C. § 1396r(e)(7)(A)(i); 42 C.F.R. §§ 483.104, 483.106, 483.128. The process is designed to identify individuals with mental illness and intellectual and developmental disabilities, and determine whether those individuals' needs can be met in the community. 42 C.F.R. §§ 483.128(a), 483.132(a).

personal attendant services – a process known as self-direction – or face termination. Self-direction generally enables individuals with disabilities to maintain control and choice over services they receive, the people who provide them, and the way in which those services are provided. However, many individuals need supports to assist them in self-directing their care. In other states, comparable programs provide, for example, coaches who are available to help with hiring and managing workers and registries of pre-screened and trained workers so individuals do not have to rely on placing newspaper ads to find staff. The Quadriplegia Waiver program offers some support to individuals to assist with self-direction after they independently interview and select their provider. But this mandatory requirement, coupled with lack of sufficient support services for self-direction, poses a significant challenge to accessing services, and many recipients found hiring burdensome. The limitations likely screen out individuals who would prefer community services and would otherwise be eligible for this program. The goal of self-directed programs should be to provide an option to support individuals to have as much autonomy, control, and flexibility in obtaining services as they desire, but as it is used in South Dakota's Quadriplegia Waiver program, it is instead creating a burden for some individuals to access community services.

Services under each waiver program also appear to be limited in quantity. In the Quadriplegia Waiver program, personal attendant services are capped at 42 hours per week, an average of six hours per day. While there are no prescribed hourly caps on Home Services Waiver program services, there is a widespread belief, especially among people with disabilities and community providers, that these services are significantly limited. This is borne out by the State's own data, which shows that service plans contain a median of only 3.5 hours of personal care per week and, with the exception of 11 individuals, no one in this program is assessed to receive more than 30 hours of personal care per week. The State Plan also significantly limits the amount of personal care and home health services an individual can receive each year. Providers observed that individuals who need as much as 24-hour care can be served in the community if they can privately pay for services. But for individuals who rely on Medicaid, providers are unable to support them in their homes because the State does not make sufficient hours available. As a result, individuals who can use private funds for services stay in their homes longer and are less likely to move to nursing facilities than those who rely on Medicaid.

One community-based service provider told us that at any given time, a majority of their clients were at risk for being placed in a nursing facility simply because the State had not approved a sufficient number of hours of care. For many of these individuals, this risk could be eliminated by just a few additional hours of care. Other providers echoed this sentiment, explaining that Medicaid clients are often not approved for enough care.

Individuals with particular types of needs appear to be especially unable to access services in the community and thus must move to a nursing facility to receive services. Nursing facility administrators and community providers identified dementia or other cognitive disabilities as a significant barrier for individuals to stay in the community, due to lack of appropriate services, despite the fact that community providers can serve such individuals successfully. Individuals also face barriers to living in the community when they are at risk of falling. In particular, individuals who need regular supervision and lack family support seem to be unable to obtain these services in the community. Individuals who require assistance with managing diabetes are also frequently placed in nursing facilities. Others moved to a nursing

facility because there was no dialysis facility near their home. For individuals with these types of needs, services may not exist to support them, or there may be barriers to access such as a failure to connect individuals with appropriate services.

At times, housing can be a particular barrier when the only available housing is inaccessible or when individuals require modifications to ensure their homes remain accessible as a result of newly acquired disabilities. Nursing facility residents who used wheelchairs described the challenges they faced in finding accessible, affordable housing, which caused some to cycle in and out of nursing facilities and to experience homelessness.

The State must also ensure that providers can and do provide the services individuals are assessed to need, and that providers offer backup workers when a primary worker is not available. When individuals do not receive needed services, consequences can be devastating. One resident we met became seriously ill and was placed in a nursing facility after he did not receive the services he needed. Although he had family and Medicaid caregivers who planned to visit him regularly to bring food, assist with transferring in and out of his wheelchair, and help with his other needs, he experienced a four-day gap where he was alone and had no food. Due to his diabetes, his blood sugar dropped to dangerous levels and he developed sores from remaining in his wheelchair for too long, forcing him into the hospital, which in turn transferred him to the nursing facility.

In addition, a shortage of front-line health care workers contributes to the shortage of community services. In 2012, there were only 13 home health and personal care aides per 1,000 residents over age 65 – a decrease from 18 aides per 1,000 residents over 65 in 2009. This results in a significant and growing shortage of workers necessary to provide in-home care. Abt projected that rebalancing long-term care services by reducing nursing facility use would cut estimated shortages in half, because people tend to require less intense and less skilled care in the community than nursing facilities must be staffed to provide. Abt anticipated that increasing wage rates would further reduce the shortage of workers, although neither of these strategies would fully address the shortage of front-line workers. While South Dakota has made some laudable efforts to address the shortage of front-line health care workers, the State must ensure that reimbursement rates are sufficient to attract workers, provide expanded training opportunities, and establish a communications strategy among its provider network to ensure that providers can take advantage of State initiatives. Allowing recipients of the Home Services Waiver program to hire family members will also significantly ameliorate the difficulty of finding staff, especially in rural areas, as has been shown in other states.<sup>45</sup>

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<sup>45</sup> Across the State, most people living in the community are relying on informal, unpaid support to fill gaps in paid services. Individuals who receive services in the community frequently benefit from additional assistance provided by friends, family, neighbors, and community and religious organizations, often referred to as “natural supports.” These natural supports can augment State-administered community-based care, which can improve health outcomes and save State and federal dollars over institutional care, where individuals are often cut off from their natural supports. But without robust access to sufficient community-based services, these natural supports are often insufficient to enable individuals to remain in the community long term. Moreover, overreliance on unpaid care can place a person at serious risk of nursing facility admission; often family members and friends cannot afford to work unpaid for as many hours as a person needs, and overwork without support can result in nursing facility admission. Allowing family members to be hired as paid caregivers would help alleviate these challenges. While South Dakota offers a flexible set of caregiver support services, with a maximum cost of

Transportation is similarly important to helping people remain independent at home. According to an AARP survey, approximately two-thirds of South Dakotans age 50 or older and living in rural areas consider transportation to be extremely or very important to help people remain in their homes as they age. Providers identified a lack of transportation or inability to drive as a significant barrier to individuals remaining in their homes. The State can take advantage of Medicaid and other federal funding opportunities to ensure individuals living in their homes can access transportation to work, errands, appointments, and other aspects of the community.

The State must examine each of these areas, and others, to address the limitations in its service system that create barriers to individuals' access to and receipt of services to meet their needs.

#### 5. South Dakota Significantly Limits Access to Services at Home for People with Disabilities in Rural Areas

The lack of home- and community-based services is particularly significant for people with disabilities who live in rural and frontier areas of the State, putting these individuals at significant risk of needing to seek nursing facility care. A State-commissioned report acknowledged that “[r]ural and [f]rontier areas face particularly low availability of [home- and community-based services].”<sup>46</sup> The report explained in 2007 that “[o]f the 12 counties with the lowest rate of in-home service clients, eight are frontier and four are rural.”<sup>47</sup> And as of 2014, 36 counties lacked a homemaker services agency within their borders.<sup>48</sup>

The State acknowledged in 2008 that it needed to “financially support home health services differently for rural and frontier” areas.<sup>49</sup> Providers, too, believed that additional funding should be available to be equitable for individuals in more rural areas due to the added costs of serving those areas, such as the cost of transportation to remote areas. Currently, these additional costs result in providers visiting less frequently. For example, one provider explained that if a care plan calls for visits twice a week, they have to visit once a week for twice as much time to avoid additional travel costs.

A particularly burdensome challenge to individuals in remote areas is the prohibition against hiring a family member who lives in the home through the Home Services Waiver program. The same limitation does not exist under the Quadriplegia Waiver program, and one provider recounted examples of family members successfully providing services under the Quadriplegia Waiver program in areas the provider could not serve through its own staff. With respect to one such client, the provider told us, “It provides him an opportunity to go home to

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\$5,000 per year, South Dakota can better support caregivers by ensuring workers are paid for the essential services they provide and by offering sufficient support for unpaid caregivers.

<sup>46</sup> Abt 2007 Report at 4.

<sup>47</sup> *Id.* at 47.

<sup>48</sup> Abt 2015 Report at 44.

<sup>49</sup> S.D. Dep't of Social Servs., *Meeting the Continuum of Care Needs of the Elderly in South Dakota Task Force: Report 7* (2008).

[his hometown on a reservation] that he otherwise wouldn't have. . . . You couldn't just hire someone from here to give services in [that town; it's] not possible because of distance.”

Even in some areas with denser populations, State services have become less available as providers have chosen to stop offering Medicaid long-term care services. As a result of these gaps, individuals who live in some areas of the State have no choice but to enter a nursing facility for care.

#### 6. Native Americans with Disabilities Are Particularly Affected by Lack of Community Services

For Native Americans with disabilities, accessing in-home care can be particularly challenging.<sup>50</sup> In-home care services are largely unavailable to individuals living on reservations in South Dakota, as is the case for other people who live in rural areas. We repeatedly heard that the lack of adequate services on the reservations put those who live there at serious risk of admission to nursing facilities. As a result, Native Americans often have to leave their homes and communities to live in nursing facilities that are hundreds of miles away. While relatively few South Dakotans leave their home counties to obtain nursing facility care in other counties, this occurs most often for individuals living in rural counties and counties that include reservations. Others may choose to remain in their homes without essential services, causing serious risks to their own health. Still others leave home in order to receive community-based care. One woman from Pine Ridge told us she had to move to Rapid City, approximately 100 miles away, in order to receive home- and community-based services. She told us she would prefer to live on the reservation, near her family, but that there were no service providers available there. She also told us she wished she could get a job as a secretary, but explained that she needs assistance transferring out of her wheelchair to use the bathroom and did not know how to get that kind of help. Native Americans we interviewed also had the impression that there were no in-home services available to them – and as noted above, it is an impression that is largely accurate.

Institutionalization poses unique challenges in Native American culture. Stakeholders from tribal communities told us that it is particularly important in Native American cultures to be able to remain in one's own home. Elders play an important role in their families and communities, and forcing them to leave damages this relationship. In addition, the restriction on hiring family members to provide personal care may pose a particular challenge for Native Americans. According to stakeholders in Native American communities, hiring outsiders to care for relatives is seen as a family failure, and lack of cultural competence poses a challenge when an outsider comes into the home.

Likewise, for many Native Americans, living in a nursing facility is a particularly difficult experience, where they may not speak the same language as their caregivers or their

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<sup>50</sup> To the extent South Dakota is providing services to eligible individuals with disabilities, including Native Americans, it must provide services in the most integrated settings appropriate. Many Native Americans in South Dakota are eligible for Medicaid services, regardless of whether they are a member of a federally-recognized tribe or whether they live on a reservation. South Dakota currently funds the placement of many of these individuals in nursing facilities across the State through its Medicaid program, but can instead ensure that Native Americans can access Medicaid services in their own homes and communities.

caregivers may not understand their culture. In addition, people who live on reservations may not be able to drive hundreds of miles to visit their family members in nursing facilities. Many Native Americans institutionalized in nursing facilities rarely see their families.

#### **D. South Dakota Can Reasonably Modify Its Service System to Serve People with Disabilities in Integrated Settings**

*“Nursing facilities aren’t cheap – I mean, this can’t be cheaper than creating alternatives in the home. It’s a no-brainer.” – Nursing Facility Administrator*

The State can reasonably modify its service system to provide home- and community-based services as alternatives to nursing facility placement for individuals with disabilities. The State already makes available a range of services that can support people with disabilities in their homes. These include the current array of home- and community-based services available through its Home Services Waiver and Quadriplegia Waiver programs, limited personal care and home health services through its Medicaid State Plan, and host homes, along with supports that could be made available through the Aging and Disability Resource Connections and Money Follows the Person programs. As discussed above, individuals in South Dakota with diagnoses and needs similar to those who are currently institutionalized receive services through these programs and are being supported to live in their homes. The State can modify and expand these existing services to serve all individuals who are unnecessarily institutionalized in nursing facilities or are at serious risk of nursing facility admission; ensure each person receives an appropriate amount of services to meet his or her needs; and eliminate unnecessary limitations and barriers that lead to unnecessary nursing facility admission.

The State could redirect the funds it already spends on institutional services to support people in community-based settings. Studies have repeatedly shown that providing home- and community-based services is less costly for states than institutional care. Abt’s 2007 report explained that in-home care can be more cost effective than institutional care, and the State has similarly acknowledged on multiple occasions that “community services are often cost-effective compared to institutional care on a per person basis.”<sup>51</sup> State reports explain that South Dakota “spend[s] a disproportionate percentage of Medicaid resources on institutional care” and “that it is important to take steps to encourage the appropriate utilization of less-costly community-based long term care services and supports.”<sup>52</sup>

By the State’s own admission, “[p]roviding services under the [Home Services] Waiver are proven to be cost-effective.”<sup>53</sup> Nursing facility stays in South Dakota cost an average of roughly \$38,000 annually in Medicaid spending per person. In contrast, the average cost for Medicaid services for a person through the Home Services Waiver program is roughly \$10,800, and only 32 of the people receiving services through the Home Services Waiver

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<sup>51</sup> S.D., Office of the Governor, *Medicaid Solutions Work Group: Recommendations to Contain Costs within South Dakota’s Medicaid Program: Final Report 27* (2011); 2009 State Plan on Aging at 2.

<sup>52</sup> S.D., Office of the Governor, *Medicaid Solutions Work Group: Recommendations to Contain Costs within South Dakota’s Medicaid Program: Final Report 15* (2011).

<sup>53</sup> S.D. Dep’t of Social Servs., *Medicaid Overview Report: Providing Cost-Effective Health Care to South Dakota’s Medicaid Recipients* 19, <https://dss.sd.gov/docs/news/reports/sdmedicaidreport3.pdf>.

program have a service plan costing more than an average nursing facility stay. Many people could thus receive services in the most integrated setting appropriate to their needs at a significant cost savings to the State, even with enhancements to the current array and quantity of services available in the State's home- and community-based waiver programs. With a full array of services needed to support individuals in their own homes and communities, South Dakota's savings would likely be in line with national trends. Data from the national Money Follows the Person demonstration program shows that transitioning an older adult from a nursing facility to the community reduces long-term supports and service spending by 23%; transitioning a younger individual with a physical disability reduces spending on long-term care services by roughly 32%. Applied to South Dakota's nursing facility costs, the State could save approximately \$8,750 per person for older adults with disabilities and \$12,200 for younger people with physical disabilities in Medicaid dollars each year. These savings do not include the likely additional savings that will be realized from other types of spending, such as those represented by the decreased usage of non-long-term Medicaid services that typically occurs when individuals receive adequate long-term care in the community. And savings will likely be greater for those individuals who can be diverted and never enter a nursing facility in the first place. Similarly, assisted living facilities are more costly to the State than maintaining individuals in their own homes.

In addition, the State has repeatedly missed opportunities to use federal funding to supplement its own spending and expand community-based services. Taking advantage of these opportunities would further save State funds while making additional services available.

Though the State could use existing and available resources to rebalance its service system, we found no evidence during our investigation of a comprehensive, effectively working plan designed to reduce the State's reliance on nursing facilities for individuals with disabilities. Instead, people languish for years in nursing facilities without meaningful opportunities to transition to integrated settings.

## **V. RECOMMENDED REMEDIAL MEASURES**

The State should promptly implement remedial measures to cure the deficiencies discussed above and protect the civil rights of people with disabilities who receive services in the State. These remedial measures should include:

- Increasing capacity by expanding services and addressing limitations to adequately serve, in the community, individuals who are currently living in nursing facilities or who are at serious risk of entering nursing facilities. The State must identify and remove barriers to accessing such services that result in individuals' placement in nursing facilities. Services must be culturally competent and individuals must have a meaningful choice to receive services in the most integrated setting appropriate to their needs.
- Preventing unnecessary admissions of individuals with disabilities to nursing facilities by developing a system to identify potential admissions and to promptly arrange for in-home care. The State should not rely on hospitals or nursing facilities alone to refer people to the State for services.

- Developing a system to disseminate information about community services, identify individuals in nursing facilities who are appropriate for and do not oppose community placement, and conduct adequate transition planning to ensure that people with disabilities receive services in the most integrated setting appropriate to their needs. The State must ensure that residents have an individualized, person-centered,<sup>54</sup> written transition plan that identifies the services and supports needed to successfully serve the person in the community. The State cannot solely rely, as it currently does, on the staff of nursing facilities to locate and arrange for appropriate alternative services upon an individual's discharge.
- For those individuals who currently live in, and those who have transitioned to, the community, the State must ensure that individuals are receiving necessary services in sufficient quantity to enable individuals to succeed in the community and to maximize integration with the community.

## VI. CONCLUSION

We hope to continue working with the State in an amicable and cooperative fashion to resolve the issues identified in this letter<sup>55</sup> with respect to the State's failure to provide its services and programs in the most integrated setting appropriate.

We are obligated to advise you that, in the unexpected event that we are unable to reach a resolution regarding our concerns, the Attorney General may initiate a lawsuit pursuant to the ADA if we have determined that we cannot secure compliance voluntarily, 42 U.S.C. § 2000d-1, to correct deficiencies of the kind identified in this letter. We would prefer, however, to resolve this matter by working cooperatively with the State and are confident that we will be able to do so. The Department of Justice attorney assigned to this investigation will be contacting the State's attorneys to discuss this matter in further detail. If you have any questions regarding this letter, please call Steven H. Rosenbaum, Chief of the Civil Rights Division's Special Litigation Section, at (202) 514-4713.

Sincerely,



Vanita Gupta  
Principal Deputy Assistant Attorney General

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<sup>54</sup> Person-centered planning is the formal process that organizes services and supports around a self-directed, self-determined, and goal-directed future. With the assistance of a transition planning team (made up of, as appropriate, a State representative, treating health care professionals, a nursing facility social worker, a guardian, and family members or friends), an individual identifies transition goals and the steps and services needed to transition to and successfully live in the community.

<sup>55</sup> Please note that this findings letter is a public document. It will be posted on the Civil Rights Division's website.

cc: Jim Seward  
General Counsel  
Office of the Governor  
State of South Dakota  
500 East Capitol Avenue  
Pierre, South Dakota 57501

Laura Ringling  
Division of Legal Services  
Department of Social Services  
700 Governors Drive  
Pierre, South Dakota 57501

Dennis Holmes  
Acting United States Attorney for the District of South Dakota  
325 South First Avenue, Suite 300  
Sioux Falls, South Dakota 57104