## **U.S. Department of Justice**



## Civil Rights Division

Disability Rights Section 4 Constitution Square 150 M St., NE Washington, DC 20530

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Re: <u>The United States' Investigation under Title II of the Americans with Disabilities</u>
Act of Alabama's Long-Term Care System for Children with Physical Disabilities

Dear Ms. Brooks, Mr. Offord, and Ms. Penhale:

We write to report the findings of our investigation of Alabama's long-term care system for children with physical disabilities. In response to complaints, we assessed the State's compliance with Title II of the Americans with Disabilities Act of 1990 (ADA), 42 U.S.C. §§ 12131–12134, as interpreted by the Supreme Court in *Olmstead v. L.C.*, 527 U.S. 581 (1999). Title II and *Olmstead* require public entities to administer services to individuals with disabilities in the most integrated setting appropriate to their needs. Title II authorizes the United States to initiate investigations, make findings of fact and conclusions of law, and attempt to secure voluntary compliance when it finds violations. 28 C.F.R. § 35.172.

As set forth below, Alabama violates Title II of the ADA by administering its long-term care system in a manner that unnecessarily segregates children with physical disabilities in institutions, and places others at serious risk of such unnecessary segregation. This letter provides the basis for that conclusion as follows: first, we provide a brief background on children with physical disabilities and their needs; next, we set forth the Department's findings of fact and conclusions of law; and finally, we address the steps the State can take to remedy the violation the Department has identified.

We would like to thank the State for its assistance and cooperation throughout our investigation and to acknowledge the courtesy and professionalism of all the State officials and counsel involved in this matter. We look forward to working toward an amicable resolution of the violation described below.

#### I. Summary of Findings

The Department opened this investigation in response to complaints alleging that the State's long-term care system for children with physical disabilities results in the unnecessary segregation of some children in nursing facilities and hospitals and places others at serious risk of such unnecessary segregation.

Alabama violates Title II of the ADA by failing to serve children with physical disabilities in the most integrated setting appropriate to their needs. 42 U.S.C. § 12132; 28 C.F.R. § 35.130(d); see Olmstead 527 U.S. at 597. This includes children with physical disabilities in the foster care system and children with medical and non-medical needs. The State's violation forces families to make life-altering choices. Some parents—because they cannot access medically necessary services for their children but are also balancing the demands of a job or raising other children—felt they had no option but to send their children away to nursing homes, where they have remained for years, and sometimes, for the rest of their childhoods. Other parents reluctantly leave careers to provide full-time care for their children at home because promised State services go undelivered. In short, many children with physical disabilities in Alabama are unnecessarily institutionalized or are at serious risk of unnecessary institutionalization.

Alabama's actions cause unnecessary segregation of children with physical disabilities in several ways. First, Alabama limits community-based services, known as long-term support services (LTSS), that children with physical disabilities need to live at home through restrictive authorization criteria and policies. Second, the State fails to provide critical information and appropriate referrals that would connect children to necessary services by failing to coordinate its agencies. Third, Alabama under-develops its community-based workforce to staff services for children, leaving children without access to community-based care. Fourth, the State does not use its existing case management, care coordination, or transition services programs to ensure children with physical disabilities can live at home. Finally, Alabama fails to support foster parents who care for or are considering caring for foster children with physical disabilities, leaving foster families without information and services necessary for successful home placement. As a result, some children who could otherwise be cared for in family homes have spent their formative years growing up in nursing homes, separated from their families and

communities. Others live on the brink of such institutionalization, as their families struggle physically, financially, and emotionally to keep them at home.

As detailed below, Alabama could remedy these deficiencies by reasonably modifying its service system for children with physical disabilities. Although the State has made some recent changes to this system, the changes—without more—are not enough to remedy the violation.

### II. Background: Children with Physical Disabilities and Alabama's Service System

Children with physical disabilities often need medical and non-medical services to support them. Some have complex medical needs that require 24-hour attention from an awake and alert caregiver, such as the need for tracheostomy (airway) care. Some require intermittent attention for needs like gastrostomy tube (feeding tube) feeds or have non-medical needs that can be met by personal care providers, such as assistance with bathing, using the toilet, and help getting out of bed and into wheelchairs (often referred to as transfers).

The State has reported there are more than 1,000 children in Alabama who have long-term care needs. In June 2021, according to the State, there were 1,216 of those children, with 69 of them receiving services in nursing facilities. At that same time, only 77 of the children were authorized to receive private duty nursing services at home, while the rest were authorized for non-nursing long-term care services. Some children with physical disabilities in Alabama are in the custody of the State's Department of Human Resources (DHR)—that is, they are part of the foster care system. The State determines their residential placements, as well as whether and in what setting they will receive medically necessary services. <sup>1</sup>

Alabama operates a system of long-term care services for Medicaid-eligible children with physical disabilities, including services provided in both community settings and facilities. The State offers community-based services through local provider agencies that contract with the State to perform the services. Alabama offers facility-based services in skilled nursing facilities, with most children who receive those services living in the State's two pediatric nursing facilities, both located in Montgomery. Although admission to the nursing facilities is based on an individual's need for nursing care, the pediatric facilities limit admissions of high-needs patients, including children with ventilators. As a result, in Alabama, some children living in the pediatric nursing facilities have fewer medical needs than some children with complex medical needs who live at home. Some Alabamian children with complex medical needs have been hospitalized for extended periods of time or have been placed in out-of-state nursing facilities as a result of their lack of access to sufficient services in the community.

see also Ala. Admin. Code r. 660-5-28-.07(1)(a) (DHR's responsibilities in the context of foster care).

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<sup>&</sup>lt;sup>1</sup> DHR makes placement decisions for children in foster care and must conduct permanency planning for them. For each child with complex medical needs in its custody, the State decides where the child will receive medically necessary services, *i.e.*, in a nursing facility, or in a community-based setting such as Medically Fragile Foster Care. See Ala. Code §§ 12-15-314(a)(3)(a), (a)(5) (discussing DHR's authority in implementing foster care), 12-15-315;

The State's services in the community include "private duty nursing" (PDN) services for children who need at least four hours of continuous nursing care per day, "skilled nursing" for less-frequent nursing needs, and "personal care services" for children who need non-medical assistance with activities of daily living. Alabama Medicaid administers the State's private duty nursing program, which is paid for through the Medicaid State Plan. The Alabama Department of Senior Services (ADSS), through local Area Agencies on Aging (AAAs), administers skilled nursing and personal care services funded by a Medicaid waiver program. That program, the Elderly & Disabled (E&D) waiver, serves the majority of children with physical disabilities in the State who are authorized to receive long-term support services.

Alabama is required under the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) requirements of the Medicaid Act to provide all medically necessary services, including private duty nursing and personal care services, to Medicaid-eligible children. 42 U.S.C. § 1396a(a)(43).<sup>4</sup>

### III. Findings

Alabama is failing to provide its services to children with physical disabilities in the most integrated setting appropriate to their needs, in violation of Title II of the ADA. 42 U.S.C. § 12132; 28 C.F.R. § 35.130(d). The State plans, administers, and funds its long-term care system in a manner that unnecessarily segregates some children with physical disabilities, including some children in the foster care system, in nursing facilities. These children could live in the community with adequate community-based services, and their parents and guardians do not oppose community placement. Alabama's policies and practices place many more children who currently live in the community at serious risk of unnecessary segregation.

Title II of the ADA prohibits public entities from subjecting qualified individuals with disabilities to discrimination. Public entities may not, on the basis of disability, exclude qualified individuals from participating in, or deny them the benefits of, the entity's services, programs, or activities. 42 U.S.C. § 12132; 28 C.F.R. § 35.130(a). Congress explicitly identified unjustified "segregation" of persons with disabilities as a "for[m] of discrimination." 42 U.S.C. §§ 12101(a)(2), 12101(a)(5). Title II includes an integration mandate, which requires that "a public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities." *Olmstead*, 527 U.S. at 597; 28 C.F.R. § 35.130(d). The "most integrated setting" is one that "enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible[.]" 28 C.F.R. pt. 35, app. B, at 702 (2022). Thus, a state violates the ADA when it administers and funds services

<sup>&</sup>lt;sup>2</sup> Private duty nursing services include catheter care, wound care, maintenance of gastronomy tubes (feeding tubes), administration of medications, and care for children with tracheostomies, including those who are ventilator dependent. *See* Ala. Admin. Code r. 560-X-11-.14(2)(k).

<sup>&</sup>lt;sup>3</sup> Personal care services include assistance with activities of daily living, such as eating, bathing, toileting, transfer and ambulation, skin care, therapies, and exercise. Ala. Admin. Code r. 560-X-11-.14(2)(o).

<sup>&</sup>lt;sup>4</sup> See 42 U.S.C. § 1396d(r)(5) (providing that states must provide any other health care, diagnostic services, treatment, and other measures that are "necessary").

for people with disabilities—including the services in its long-term care system—in a manner that unnecessarily segregates service recipients. *See* 42 U.S.C. § 12132; 28 C.F.R. § 35.130(d).

The Supreme Court has held that unjustified isolation is a form of discrimination prohibited by the ADA. *Olmstead*, 527 U.S. at 597. Public entities must provide community-based services to individuals with disabilities when (a) such services are appropriate, (b) the affected persons do not oppose receiving services in the community, 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. *Id.* at 607. The ADA's integration mandate applies not only to people with disabilities who are currently in institutions, but also to people with disabilities who are at serious risk of segregation. *See, e.g., Waskul v. Washtenaw Cnty. Cmty. Mental Health*, 979 F.3d 426, 460 (6th Cir. 2020) (collecting cases); *United States v. Florida*, 682 F. Supp. 3d 1172, 1185-86 (S.D. Fla. 2023), *appeal pending*, No. 23-12331 (11th Cir.). A public entity must make modifications to policies, practices, or procedures when necessary to avoid disability discrimination, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity. 28 C.F.R. § 35.130(b)(7)(i).

Below, we detail our findings on Alabama's violation of Title II's integration mandate. First, we explain that Title II of the ADA applies to Alabama and that, under the law, nursing facilities are segregated settings. Next, we discuss our findings under *Olmstead*, that community-based settings are appropriate for children with physical disabilities and that the families of these children do not oppose community-based services. Finally, we explain how Alabama's current system is causing the unnecessary segregation of children with physical disabilities and what Alabama can do to avoid this ADA violation.

# A. Alabama is a Public Entity Under Title II, and Nursing Facilities are Segregated Settings

Title II of the ADA applies to the State of Alabama because it is a "public entity" as defined by the statute. 42 U.S.C. § 12131(1). Alabama is prohibited from discriminating on the basis of disability, directly or through contractual, licensing, or other arrangements. 28 C.F.R. § 35.130(b)(1).

It is well established that nursing facilities are segregated settings because they only permit the admission of individuals with disabilities. *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). Alabama's pediatric nursing facilities are no different; the facilities admit only children with disabilities.<sup>5</sup>

Like most nursing facilities, Alabama's pediatric nursing facilities are designed like hospitals, with long hallways connected by nursing stations. Multiple children live in each of the rooms along these hallways. Children living in these facilities have few opportunities for interaction with individuals without disabilities, apart from facility staff, and they rarely leave the facility grounds other than the group of children who go to a local public school for children

<sup>&</sup>lt;sup>5</sup> See Ala. Admin. Code r. 560-X-10-.10 (setting forth nursing facility admission criteria).

with disabilities. Those children who do not leave the building for school stay in their beds, some enclosed by metal bars or in their wheelchairs beside their beds.

## B. Community-Based Settings Are Appropriate for Children with Physical Disabilities

All of the children living in Alabama's pediatric nursing facilities could live with families and in their communities with appropriate services and supports. Indeed, many children in nursing facilities were institutionalized, and remain in nursing facilities for years of their lives, because they need non-medical care they cannot access in the community. Multiple children with physical disabilities live in Alabama nursing facilities because they grew too big for their parents to lift them; without the community-based services to which their children are entitled, they had no choice but to seek care from a nursing facility.

Because the State does not serve children with the highest medical needs in the pediatric nursing facilities, those children are already living at home. But because the State limits access to community care, many children with complex medical needs in Alabama have lived for months at a time in the hospital, long after they are medically ready for discharge, when they could be going to school and living with their families.

Regardless of whether these children have complex medical needs, the children's disabilities do not necessitate their institutionalization. Access to community-based services would allow Alabamian children with physical disabilities, including children with complex medical needs, to have active lives and be integrated in their communities, including socializing with their peers and attending public schools and religious services, as well as pursuing higher education, without the serious risk of unnecessary segregation in nursing facilities or hospitals. And access to community-based services could allow Alabama families whose children are currently living in nursing facilities to be able to bring their children home.

## C. Alabama Families of Children with Physical Disabilities Do Not Oppose Community-Based Services

Alabama families of children with physical disabilities, including children with complex medical needs and children in the foster care system, do not oppose receiving services in integrated, community settings. Families' lack of access to personal care and private duty nursing services in the home—not opposition to community living—is often their primary reason for resorting to institutionalization. Families living without services that are ostensibly offered by the State struggle both to provide the full-time care their children with disabilities need and maintain jobs and care for other family members. After years without support, many families must choose between keeping their children in their homes and losing or quitting their jobs. Foster families who would have continued to care for foster children with physical disabilities in their homes also face difficult decisions; several children in Alabama nursing facilities were placed there because their foster families, after trying for years to care for the children, could no longer do so without needed services or supports.

# D. Alabama's Current System Causes Unnecessary Segregation of Children with Physical Disabilities

While Alabama offers some services in community settings for children with physical disabilities, the State limits access to those services in the following ways, resulting in children's admission to hospitals and nursing facilities, while placing others at serious risk of such institutionalization.

Restrictive Service Authorization and Failure to Maintain Community-Based Providers

Through both policy and practice, Alabama fails to authorize medically necessary services for children with physical disabilities living in the community. The State's strict criteria for private duty nursing authorization excludes even children who rely on medical equipment to survive<sup>6</sup> and, in some cases, may depart from treating physicians' recommendations without explanation or justification. Alabama also maintains other policies that restrict service authorization for reasons unrelated to medical necessity. For example, the State will not authorize private duty nursing services, even when they are medically necessary, based on a purported "convenience" of the caregiver. The Medicaid Provider Manual limits private duty nursing hours such that families may not be able to access services sufficient to allow parents to work or to sleep.<sup>8</sup> That manual also states that service requests may be denied based solely on the number of family members a child has or the area of the State in which the child lives.<sup>9</sup> These written policies have stark consequences for children with physical disabilities and their families. Some parents in Alabama, after experiencing years of denied requests for prescribed private duty nursing services, have given up on receiving those services, causing financial and, in some cases, physical, hardship for their families, and placing their children at serious risk of institutionalization.

Alabama further restricts its community-based services for children by limiting the number of service hours a child can receive based on perceived parental availability and competence. For example, the State will reduce authorized private duty nursing hours over time if it determines that the parent knows how to perform nursing functions for their child, with only temporary hours increases in extraordinary situations or in the event of a new diagnosis. In this way, the State relies on parents to provide skilled care without regard to whether this places the child at serious risk of institutionalization.

And when the State does authorize provider-paid skilled services, children do not receive them because Alabama fails to adequately fund, develop, and maintain a community-based workforce to staff services for children. The State refers children who cannot locate available

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<sup>&</sup>lt;sup>6</sup> For example, a child who uses a ventilator may qualify for private duty nursing, but only if they require ventilation for at least six hours per day. If not, they may qualify for the service only if the ventilator settings must be changed at least every eight hours, or if they require a certain amount of oxygen supplementation. *See* Ala. Medicaid, Ala. Medicaid Mgmt. Info. System Provider Manual 31-7 (Oct. 2024).

<sup>&</sup>lt;sup>7</sup> See Ala. Admin. Code r. 560-X-11-.14(2)(k)(6)(iii); Ala. Medicaid, *Private Duty Nursing Agreement for Care* (Rev. June 2012), https://medicaid.alabama.gov/documents/9.0\_Resources/9.4\_Forms\_Library/ 9.4.3\_Consent\_Forms/9.4.3\_Form\_388\_PDN\_Agreement\_for\_Care\_6-18-12.pdf (last visited Jan. 10, 2025).

<sup>&</sup>lt;sup>8</sup> Private duty nursing hours "may be provided for *up to* eight hours [for sleep] depending on the situation of the primary caregiver . . . [A] single parent with no other family support may be granted a full eight hours, while two parents . . . may require fewer hours or only hours on an occasional basis." *See* Ala. Medicaid, Ala. Medicaid Mgmt. Info. System Provider Manual 31-4 (emphasis added) (Oct. 2024).

<sup>&</sup>lt;sup>9</sup> See Id at 31-3.

community-based providers to its "self-directed" program, which allows Medicaid to reimburse families to provide the care themselves. <sup>10</sup> However, the State limits the services available under this program, so children whose families resort to self-direction in the absence of available providers may still be unable to access all medically necessary services. Indeed, some children are on the brink of nursing facility placement for this reason.

#### Failure to Provide Necessary Information and Make Referrals

Alabama fails to coordinate its agencies to provide necessary information and make appropriate interagency referrals, thereby restricting the services children can receive at home. For example, local Medicaid offices screen individuals for the Medicaid State Plan based on income requirements but do not generally, even if a child is already Medicaid-enrolled and the need is clear, tell parents that the child could receive necessary services through a waiver, regardless of family income. Likewise, the entities that administer the Medicaid waiver (the Area Agencies on Aging) will not provide their waiver clients any information about or assistance applying for private duty nursing services, even if the need is clear, because private duty nursing is funded through the State Plan. This results in children with physical disabilities getting access to services based on the agency their families happen to contact, rather than the children's needs.

Despite Alabama's receipt of a \$2.36 million federal grant over three years through the No Wrong Door System Initiative to make information accessible across all State agencies, the State's failure to coordinate its agencies also results in inconsistent, and sometimes inaccurate or misleading, information given to families. Similarly, the State makes publicly available Medicaid eligibility and service descriptions but omits or misstates critical information, impeding access to services. For example, Alabama's information for families about EPSDT fails to mention the program's required coverage of personal care services and private duty nursing as treatment services. State information also erroneously suggests that children are eligible only for treatment to prevent permanent, lifelong disability. Additionally, the State's publicly available information on waiver eligibility criteria gives the impression that a child

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<sup>&</sup>lt;sup>10</sup> Ala. Medicaid "Personal Choices", https://medicaid.alabama.gov/content/6.0\_LTC\_Waivers/6.3\_Other\_LTC\_Programs/6.3.3\_Personal\_Choices.aspx (last visited Jan. 10, 2025).

<sup>&</sup>lt;sup>11</sup> According to a Medicaid announcement of the initiative, the State intended to pay for training to ensure that, regardless of which agency a family chooses to call to inquire about community-based services, information should be accessible across all agencies to allow families to make informed decisions. Ala. Medicaid "Alabama one of five states chosen for 'No Wrong Door' Grant", https://medicaid.alabama.gov/documents/1.1\_MM/1.1\_MM\_No\_Wrong\_Door\_10-29-15.pdf (last visited Jan. 10, 2025).

<sup>&</sup>lt;sup>12</sup> The fact sheet describes EPSDT as follows: "Medicaid's Well Child Check-Up program is...designed to find children with...health problems...and treat the problems before they become permanent, lifelong disabilities." Ala. Medicaid, What is EPSDT?, https://medicaid.alabama.gov/documents/4.0\_Programs/4.2\_Medical\_Services/4.2.3 EPSDT/4.2.3 Fact Sheet Revised 11-16-22.pdf (last visited Jan. 10, 2025).

would be denied waiver access based solely on parental income. <sup>13</sup> In fact, a child's income, not the family income, may be determinative.

Parents in Alabama spend years attempting to piece together publicly available information on community-based services from state resources, and despite these efforts, parents are still resorting to nursing facility placement as a result because they ultimately cannot access these services.

Lack of Effective Case Management, Care Coordination, and Transition Services

Although Alabama has systems in place to connect Medicaid recipients in nursing facilities and those at serious risk of admission to community-based services, the State rarely uses these systems to support children. For example, Alabama's Integrated Care Network (ICN) provides coordination of medical care to individuals who receive their Medicaid-funded services through nursing facilities or the E&D waiver. <sup>14</sup> The goal of the Integrated Care Network is to provide individuals services in the least restrictive setting of their choice. <sup>15</sup> But several years after the program began in 2018, the State had not used the Integrated Care Network to help any children move from institutions to receiving services in community homes. As for children living in the community, the State restricts Integrated Care Network eligibility in a way that may prevent access for children who live with ongoing, high care needs that have remained constant over time. Integrated Care Network eligibility is generally determined by the number of hospital admissions and new diagnoses or changes to one's condition. This means that children who have high medical care needs but insufficient services—those who are likely most at risk of institutionalization—may not qualify for the Integrated Care Network, as long as their needs reflect a baseline condition and not a new diagnosis or hospitalization.

When Alabama does use its coordination programs other than the Integrated Care Network to connect children with physical disabilities to services, there are still children that cannot access those programs and therefore do not get the services they need at home. For example, the Alabama Coordinated Health Network (ACHN) provides care coordination services to children with complex medical needs. But this network serves these children only in certain regions of the State, and referrals may cover only those children leaving hospitals. This system leaves others currently living in the community who may not be aware of their eligibility for services such as private duty nursing without assistance.

While the State has services to assist individuals living in institutions in making the transition to living at home with appropriate community-based services, it has failed to provide children with access to those services. Alabama has received over \$16 million in federal funds

<sup>&</sup>lt;sup>13</sup> See Ala. Medicaid, Home and Community-Based Waivers – 2024, available at https://medicaid.alabama.gov/documents/3.0\_Apply/3.2\_Qualifying\_Medicaid/3.2.1\_Medicaid\_for\_Children\_POC Rs/3.2.1 Revised Form 206 Waiver HBCS 9-24-24.pdf (last visited Jan. 10, 2025).

<sup>&</sup>lt;sup>14</sup> The program also serves individuals receiving services under the Alabama Community Transition (ACT) waiver. *See* Ala. Admin. Code r. 560-X-64-.16 - .17.

<sup>&</sup>lt;sup>15</sup> Ala. Medicaid "Integrated Care Network Fact Sheet", https://medicaid.alabama.gov/documents/5.0\_ Managed\_Care/5.2\_Other\_Managed\_Care\_Programs/5.2.4\_ICNs/5.2.4\_ICN\_Fact\_Sheet\_10-23-18.pdf (last visited Jan. 10, 2025).

to operate a nursing facility transition program. <sup>16</sup> But it has used few of those resources to assist children. From January 1, 2017 to June 2021, that program served only *nine* of the over 130 children residing in nursing facilities during that time. Of the nine institutionalized children served by Alabama's transition program, Alabama successfully transitioned only *six* back to their communities; the other three remained in nursing facilities.

#### Failure to Support Foster Parents of Children with Physical Disabilities

Although state law requires it,<sup>17</sup> Alabama fails to support foster families with the information and services they need to care for foster children with physical disabilities at home. This failure persists despite foster children's automatic enrollment in Medicaid and eligibility for all medically necessary services under EPSDT. Alabama's placement policies for children with physical disabilities do not mention the variety of Medicaid-funded services that the State may be required under EPSDT to offer children in foster care. Instead, DHR manuals suggest that families that choose to foster children with physical disabilities would be expected to provide all medically necessary care, including nursing services, on their own.<sup>18</sup>

Foster parents who provide homes to children with physical disabilities in Alabama do not receive the information, training, and services they need to maintain the placements. For example, DHR places some children with significant physical needs, including complex medical needs, in foster homes without first providing the foster family with any information about the child's disability or daily care needs. In these circumstances, foster families have had to resort to personal networks and, in some cases, websites like YouTube, to figure out how to provide medical- and disability-related care for their children. DHR also denies foster children with physical disabilities access to medically necessary services, despite direct and repeated requests from foster parents. And DHR fails to affirmatively offer services like private duty nursing and personal care services to support placements, even while asking current foster parents of children with physical disabilities to take more children with significant needs into their homes. Multiple foster parents, who have fostered more than a dozen children with complex medical needs have never received any PDN services for them. DHR's failure both to appropriately prepare foster families to care for children with physical disabilities and to support the families with access to medically necessary services, has resulted in unnecessary nursing facility placements of some foster children and left those living with foster families at serious risk of such unnecessary segregation.

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<sup>&</sup>lt;sup>16</sup> Ctrs. for Medicare & Medicaid Servs., "Total MFP grant awards and initial award dates" (FY 2022) *available at* https://www.medicaid.gov/sites/default/files/2022-05/mfp-grant-awards-04052022.pdf (last visited Jan. 10, 2025).

<sup>&</sup>lt;sup>17</sup> State law requires that foster parents receive information in advance of placement that will allow them to meet children's daily care needs. *See* Ala. Admin. Code r. 660-5-28-.07 (setting forth procedures applicable to any type of foster care); Ala. Admin. Code r. 660-5-29-.06 (setting forth provider requirements for foster family homes serving medically fragile children).

<sup>&</sup>lt;sup>18</sup> "Foster care providers for medically fragile children must provide a specialized service based on the child's individualized needs that are beyond 'ordinary parental duties.' A difficulty of care rate has been established to reflect the services being rendered by foster parents for those children identified as medically fragile." Ala. Dep't of Human Res., *Health/Medical Care Manual* 10 (Rev. Aug. 9, 2021).

Once DHR places foster children in nursing facilities, the agency makes no documented efforts to locate viable community placements for them or to appropriately support them with services. Frequently having no other advocates, these foster children are left for years, sometimes permanently, in nursing facilities.

## IV. Alabama Can Reasonably Modify its Existing System to Avoid Discrimination

Alabama could reasonably modify its existing service system, without fundamentally altering it, to prevent unnecessary segregation of children with physical disabilities in nursing facilities. 28 C.F.R. § 35.130(b)(7)(i); *Olmstead*, 527 U.S. at 603, 607. Such modification would allow children with physical disabilities who need long-term care services, including children with complex medical needs and children in the foster care system, to live in community homes.

The types of services needed to support children with physical disabilities in community settings already exist in Alabama and cost less than nursing facility and hospital placement. And, under the Medicaid Act's EPSDT provisions, the State already must provide these services to all Medicaid-eligible children, making modifications that would result in Alabama meeting its existing obligation inherently reasonable.

Moreover, because the modifications listed below build on the State's existing framework for providing services and enable the State to more fully utilize and expand that framework to make the services truly accessible, they are reasonable. *See, e.g., Florida*, 682 F. Supp. 3d at 1241; *see also, e.g., Haddad v. Arnold*, 784 F. Supp. 2d 1284, 1304-05 (M.D. Fla. 2010); *Messier v. Southbury Training Sch.*, 562 F. Supp. 2d 294, 344-45 (D. Conn. 2008).

## V. Alabama Could Remedy Its Violations

Alabama could remedy these violations to allow children with physical disabilities, including children with complex medical needs and children in the foster care system, to live in homes and communities and grow up with families rather than in institutions. *See* 28 C.F.R. § 35.130(b)(7)(i), (d). To this end, Alabama could make reasonable modifications such as:

- Modifications that will ensure access to community-based services and settings for children with physical disabilities in Alabama, including children with complex medical needs and children in the foster care system, preventing their unnecessary segregation in nursing facilities and hospitals;
- Modifications that will ensure families of Medicaid-eligible children with physical disabilities regularly receive plain language, accurate, and accessible information about eligibility requirements for Medicaid and Medicaid waiver programs and available community-based services, as well as prompt assistance in securing those services;

<sup>&</sup>lt;sup>19</sup> The efforts DHR does make are focused on identifying able family members with whom to place the children, a process that can take years to resolve, if ever. Meanwhile, DHR maintains the children's placement in nursing facilities indefinitely, while failing to recruit and support with appropriate services families to provide integrated placements in community homes.

- Modifications to service authorization policies and practices to ensure Medicaid-eligible children for whom private duty nursing or personal care services are medically necessary can receive those services, and that medically necessary services that prevent unnecessary institutionalization are not inappropriately reduced or denied;
- Modifications to case management and care coordination programs to prevent unnecessary admissions of children with physical disabilities to nursing facilities and hospitals by establishing procedures for early identification and prompt assessment of such children, and arrangement of appropriate community-based services;
- Modifications that will ensure community provider availability, including providers available to children enrolled in the Personal Choices or any "self-directed" program, to meet demand for community-based services for children with physical disabilities;
- Modifications to transition services programs that will ensure families have an informed choice as to whether to transition their children to the community and can promptly and safely do so;
- Modifications to foster care policies and procedures to (a) expand the availability of Medically Fragile Foster Care homes to meet the needs of all eligible children with physical disabilities in the foster care system; (b) provide regular, comprehensive training to all DHR caseworkers regarding the Medicaid and other services and supports available to foster care children with physical disabilities, including children with complex medical needs, in their homes and communities, and explaining what steps caseworkers must take to ensure children have access to those services; (c) provide children with physical disabilities in foster care with appropriate, person-centered case management and care coordination services; (d) provide comprehensive training for all Medically Fragile Foster Care parents on the care needs of every child with physical disabilities they foster, prior to the child's placement; and (e) provide children with physical disabilities in foster care the in-home services they need to stay in their foster homes and avoid unnecessary nursing facility admission; and
- Modifications to increase coordination between state entities, including state agencies
  and their contractors and vendors, to ensure that necessary community-based services for
  children with physical disabilities are delivered with sufficient inter-agency support to
  provide services that would allow each child to succeed in a community-based setting.

We hope to work cooperatively with you to resolve the Department's findings and agree on changes the State will make to remedy the violations. If Alabama will not negotiate, or if our negotiations fail, the United States may take appropriate action—including filing a lawsuit —to remedy the State's ADA violation.

Please contact Nicole Kovite Zeitler, Trial Attorney at the Disability Rights Section of the Civil Rights Division, at (202) 598-7166 by January 30, 2025 if the State of Alabama is

interested in working with the United States to reach a resolution along the lines described above. If you have any questions as you review this letter, please feel free to contact us.

Sincerely,

/s/ Kristen Clarke
Assistant Attorney General
Civil Rights Division

cc: General Counsel, Alabama Department of Mental Health