Case Explainer:
United States v. Florida

Prepared by Arielle Linsey and Jane Perkins

On July 14, 2023, the Southern District of Florida issued a significant decision in *United States v. Florida*,[1] a case brought by the United States to address deficiencies in Florida's provision of in-home private duty nursing (PDN) and other in-home services for children with medically complex conditions (MCCs). The case is now on appeal at the Eleventh Circuit to be heard the week of January 22, 2024.[2] This case explainer discusses the decision and pending appeal.

The District Court Decision

a. Background and Factual Findings

On July 22, 2013, the United States filed a lawsuit against the State of Florida, alleging that Florida violated the Americans with Disabilities Act (ADA) by discriminating against children with MCCs by failing to administer services in the most integrated setting appropriate.[3] The lawsuit followed a six-month long investigation where the United States found Florida was unnecessarily segregating approximately 140 children with MCCs in nursing facilities and placing more than 1,800 other children at serious risk of unnecessary segregation.[4] When the United States determined it could not obtain voluntary compliance from Florida, it filed suit.[5]

At trial, the United States presented its case that the children were not receiving recommended and necessary services in the community, leading to systemic

[1] *United States v. Fla.*, No. 12-CV-60460, 2023 WL 4546188 (S.D. Fla. July 14, 2023), *appeal docketed*, No. 23-12331 (11th Cir. July 17, 2023) (hereinafter Dist. Ct. Op.).
[2] *See generally* Order, *United States v. Fla.*, No. 23-12331, (11th Cir. Sept. 5, 2023) (ECF No. 20) (setting briefing schedule); Brief of the State of Florida, *United States v. Fla.*, No. 23-12331, (11th Cir. Sept. 18, 2023) (ECF No. 22) (hereinafter Florida App. Br.); Brief for the United States, *United States v. Fla.*, No. 23-12331, (11th Cir. Sept. 18, 2023) (ECF No. 32) (hereinafter United States Resp. Br.); Notice to Counsel, *United States v. Fla.*, No. 23-12331, (11th Cir. Oct. 10, 2023) (ECF No. 29) (setting oral argument date).
[3] Dist. Ct. Op. at *8.
[4] *Id.* at *3, *8.
[5] *Id.* at *8.

institutionalization.[6] The Court heard testimony from family members, medical doctors, nursing facility staff, experts in Medicaid policy and data analysis, and representatives from state agencies, among other witnesses.[7] Both sides introduced exhibits consisting of thousands of pages of documents.[8] The Court found that Florida is failing to provide recommended and necessary PDN and other services to children with MCCs, relying on evidence such as:

- **Data Analysis from the United States' Expert.** "[O]ne of the nation's leading experts in Medicaid program policy, structure, and financing,"[9] Dr. Sally Bachman, found that 58% of children received less than 80% and 25% of children received less than 60% of their authorized PDN hours, which is a "major deviation from the amount of authorized care they are entitled to receive."[10] Dr. Bachman "found no patterns based on where children resided, either by geographic variation (rural v. urban) or population size" and "opined that based on her review of data by counties, a national nursing shortage is *not* primarily responsible for the gaps in providing PDN."[11] Based on Dr. Bachman's assessment—along with other witness testimony—the Court found it "to be undoubtedly true" that "Florida does not sufficiently serve children with medical complexity in the community in terms of the provision of private duty nursing services."[12]

- **Testimony Showing that Lack of PDN is a Widespread Problem Resulting in Institutionalization.** The Court noted that four of the children whose families testified were "institutionalized for some period of time as a direct consequence of lack of PDN."[13] One of Florida's own witnesses "confirmed that the lack of around-the-clock nursing was the biggest obstacle to discharging children with medical complexity home" and spoke of three children who were institutionalized "*as a direct result* of their families' lack of access to reliable PDN."[14] From testimony such as this, the Court concluded that "the lack of PDN is a huge barrier to children with medical complexity living in a home or community setting."[15]

- **Testimony about Care Coordination Failure.** Care coordination is a service usually provided by a nurse or social worker to ensure that a child's care plan is delivered in the manner intended.[16] The Court heard testimony demonstrating that care coordinators are

[6] *See id.* at *3-*4.
[7] *See id.* at *3.
[8] *Id.*
[9] *Id.* at *24.
[10] *Id.* at *27.
[11] *Id.* at *28 (emphasis added).
[12] *Id.*
[13] *Id.* at *29.
[14] *Id.*
[15] *Id.* at *30.
[16] *Id.*

unable to facilitate families' access to PDN; that parents and caregivers are often given no information or misinformation; that the transition planning process (to send a child home from a nursing facility) is confusing and fraught with hurdles that should not exist; and that Florida has not developed sufficient reporting mechanisms and tools for data collection to oversee how care coordination is being provided.[17]

- **Testimony about iBudget Waiver Program Waiting Lists.** Florida's iBudget Waiver program provides services such as environmental accessibility adaptations, respite care, durable medical equipment, consumable medical supplies, and transportation services that make it possible for the person to live in the community.[18] Dr. Bachman testified that 500-800 children with MCCs—including 19 children living in nursing facilities—were on the iBudget waiver program waiting list.[19] The waitlist "reflects a tremendous gap in service availability" because children on the waiting list have already been determined eligible for the iBudget Waiver.[20] Thus, children on the waiting list "indicates that Florida's Medicaid program does not sufficiently serve those children in the community."[21]

- **Testimony about Medical Foster Care Program Waiting Lists.** Florida's Medical Foster Care Program allows children with complex medical conditions to live in medical foster homes rather than more restrictive nursing facilities.[22] After hearing witness testimony about how 40-50 children, including seven children in state custody, were deemed eligible for the program but still awaiting placement, the Court found that Florida offered "no evidence that it is working to match specific children now in nursing facilities with parents."[23]

The Court found that "all of the failings described above are contributing to the unnecessary institutionalization of children with complex medical needs and placing many other children at serious risk of such unnecessary institutionalization."[24] In particular, lack of access to PDN was "by far the most glaring and critical problem" and "is causing systemic institutionalization."[25] The Court was "convinced that the State is failing to administer its services in the most integrated setting appropriate to the needs of the children at issue in this case."[26]

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[17] *Id.* at *30-*33.
[18] *Id.* at *34.
[19] *Id.*
[20] *Id.*
[21] *Id.* (The Medicaid Early and Periodic Screening, Diagnostic and Treatment provisions entitle these children to coverage of many of these services, so they should not be on a waiting list for them. 42 U.S.C. §§ 1396a(a)(10)(A), 1396a(a)(43), 1396d(a)(4)(B), 1396d(r)(5)).
[22] *Id.* at *34-*35.
[23] *Id.* at *34-*36.
[24] *Id.* at *36.
[25] *Id.* at *3.
[26] *Id.* at *36.

b. *Olmstead* Findings

Under *Olmstead v. L.C. ex rel. Zimring*,[27] a state must provide services to people with disabilities in the community, instead of institutions, when: (1) community placement is appropriate; (2) the transfer from institutional care to a less restrictive setting is not opposed by the affected individual; and (3) the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others with disabilities.[28] If Florida's administration of a program discriminates against people with disabilities, then the remedy is to modify the program, unless Florida can prove that such modification would fundamentally alter it.[29]

i. Community Placement is Appropriate.

The Court explained that community placement is appropriate under *Olmstead* if children "could live in the community with sufficient services for which they would be eligible."[30] For the more than 1,800 at-risk children, the Court noted that the families who testified are all currently receiving services, such as PDN, which enable them to live at home, even if precariously.[31] The Court found that it can hardly be disputed that this population is appropriate for community living (with services) because they have already been living in the community.[32]

For the approximately 140 institutionalized children, the Court found that community placement is appropriate based on evidence presented by Dr. Carolyn Foster, one of the United States' experts and a renowned pediatrician specializing in the care of children with MCCs.[33] Dr. Foster and two other pediatricians conducted individualized reviews of the medical records of the institutionalized children and toured all three pediatric nursing facilities in Florida.[34] They concluded that the institutionalized children do not need to live in pediatric nursing facilities so long as they have necessary community-based resources and services.[35] Dr. Foster also testified that the needs of these children "did not differ greatly from the medically fragile children that she routinely sees in her own practice" and "who reside at home" like the "vast majority of children with medical complexity."[36]

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[27] 527 U.S. 581 (1999).
[28] Dist. Ct. Op. at *5 (citing *Olmstead*, 527 U.S. at 587, 607 and 42 U.S.C. § 12132).
[29] *Id.*
[30] *Id.* at *37.
[31] *Id.* at *45.
[32] *See id.*
[33] *Id.* at *38, *40.
[34] *Id.* at *40.
[35] *See id.* at *40-*42 & n.41,*45.
[36] *Id.* at *41.

As an independent and alternative ground for a finding of appropriateness, the Court noted that many of the institutionalized children have already been deemed eligible for community-based services, which supports a finding that Florida itself already deemed them capable of living in the community with access to those services.[37]

The Court rejected Florida's argument that appropriateness should take into account a child's specific home environment, commenting that this would involve "an evaluation of barriers that might exist to home placement, which are outside the families' control but often *within* the State's control."[38] The Court also rejected Florida's argument that in some instances institutionalization is a "better" or "more appropriate" option, finding aspects of this speculation by Florida's expert to be "patronizing, disrespectful to parents, and oblivious to the life circumstances of many people who lack substantial financial resources."[39]

ii. The Families are Not Opposed to Community Placement.

The Court explained that the relevant question for non-opposition is whether service recipients with disabilities would choose community-based services if they were actually available and accessible.[40] To research whether the parents in this case opposed or did not oppose community placement for their children, the United States' experts developed and conducted semi-structured interviews with parents.[41] After twenty-one interviews, the experts reached a point of data "saturation" where they had confidence that they had a robust understanding of participants' experiences and no new themes were likely to emerge.[42] Nevertheless, they went on to conduct a total of forty-five interviews to further reinforce their findings.[43] At that point, the experts concluded that the 140 families overwhelmingly did not oppose community placement for their children.[44] The Court also noted that "[e]ven without a formal interview process and expert study, it was clear to me in listening to the testimony at trial that the dominant sentiment of families was that they wanted to be able to care for their children at home."[45]

The Court rejected Florida's argument that non-opposition should also consider real-world conditions and whether parents have the present ability to care for their child at home.[46] The Court responded that the question cannot be "whether persons with disabilities (or, in this

[37] *Id.* at *43.
[38] *Id.* at *37.
[39] *Id.* at *44, *45.
[40] *Id.* at *47.
[41] *See id.* at *47-*48.
[42] *See id.*
[43] *Id.* at *48.
[44] *Id.*
[45] *Id.* at *49.
[46] *See id.* at *47.

case, their parents or guardians) would accept discharge to the community today, with inadequate access to community-based services" because that "would defeat the purpose of the integration mandate."[47]

iii. Reasonable Accommodations Can Be Made.

The United States' expert, Dr. Bachman, identified what she believed were reasonable accommodations that Florida could make to address its failure to deliver PDN services, including more robust data collection, investigating network adequacy standards, and examining reimbursement rates.[48] She also proposed suggestions to improve care coordination, the waiting lists for the iBudget Waiver and Medical Foster Care programs, and oversight mechanisms, such as holding managed care organizations accountable pursuant to their "extremely detailed and demanding" contracts "requiring 100% delivery of services."[49]

The Court was convinced that the United States identified modifications that would call for "expanding access to state services that already exist, and for using existing State programs and tools of program administration to expand such access" such that the United States met its *prima facie* burden of articulating a plausible modification.[50] "The modifications also comport with Florida's own standards and obligations" and "because the State already must make medically necessary services accessible to all Medicaid-enrolled children with medical complexity, meeting this obligation is inherently reasonable."[51]

Once the United States identified these modifications, Florida "had ample opportunity to present a substantial modification defense" pertaining to the United States' proposed reasonable accommodations but it "chose not to do so, and it has suffered no prejudice."[52]

c. Relief Ordered

Based on the evidence produced at trial, the Court issued an injunction that requires reasonable modifications to Florida's policies, practices, and procedures.[53] The injunction has

[47] *Id.*
[48] *See id.* at *51-*52.
[49] *See id.* at *53-*54, *12.
[50] *Id.* at *54.
[51] *Id.* at *55 (internal citations omitted).
[52] *Id.* at *56.
[53] Order of Injunction, *United States v. Fla.*, No. 12-CV-60460, (S.D. Fla. July 14, 2023) (ECF No. 1171) (hereinafter Dist. Ct. Order of Inj.); *see also* Dist. Ct. Op. at *56 (emphasizing that "[t]he remedy ordered is specific and tailored to make essential changes quickly").

an anticipated term of twenty-four months (assuming reasonable progress is made), and a Court-appointed monitor will work with the parties to assess compliance.[54]

The injunction principally requires Florida to cause all Medicaid-enrolled children with complex medical needs to receive at least 90% of their authorized PDN hours with the exception of any hours refused by the child's guardian or unused because the child was hospitalized.[55] Issuing this order, the Court noted that, even though the Medicaid Act requires Florida to provide all medically necessary services (including authorized PDN) and Florida's own contracts with MCOs require a 100% provision of PDN, a 90% PDN utilization ratio would "go a long way in helping children in nursing facilities transition to home or a community setting and reduce the risk that those already living at home would be forced to move into a nursing facility."[56]

Additional specified injunctive relief requires Florida to increase oversight over care coordination,[57] take steps to facilitate transitioning children from nursing facilities to the community when desired by families,[58] and collect and maintain categories of data.[59]

Appeal in the Eleventh Circuit

Shortly after the District Court issued its decision in July, Florida filed a notice of appeal and a motion to the District Court for a stay pending appeal.[60] The motion was rejected.[61] A

[54] *See* Dist. Ct. Order of Inj. at 11, 8-10; Order Appointing Monitor, *United States v. Fla.*, No. 12-CV-60460 (S.D. Fla. Aug. 29, 2023) (ECF No. 1188); *see also* Exhibit A to The State of Florida's Notice of Selection of Monitor, *United States v. Fla.*, No. 12-CV-60460 (S.D. Fla. Aug. 18, 2023) (ECF No. 1181-1) (curriculum vitae of appointed monitor, Stephen Fitton).
[55] *See* Dist. Ct. Order of Inj. at 1-5. The Court also listed various tools Florida might use to comply with the injunction such as raising rates or establishing payment and network requirements for managed care organizations. *See id.* at 4-5.
[56] Dist. Ct. Op. at *59.
[57] *See* Dist. Ct. Order of Inj. at 5-6 (listing requirements such as establishing a training curriculum and preventing care coordinators' caseloads from exceeding certain numbers).
[58] *See id.* at 6-7 (listing, for example, requirements for creating and updating a transition plan based on when a child with complex medical conditions is admitted into a nursing facility).
[59] *See id.* at 4, 7-8 (including, for example, data on PDN hours authorized and delivered to each child with complex medical needs).
[60] The State of Florida's Notice of Appeal, *United States v. Fla.*, No. 12-CV-60460 (S.D. Fla. July 17, 2023) (ECF No. 1172); The State of Florida's Mot. for Stay Pending Appeal, *United States v. Fla.*, No. 12-CV-60460 (S.D. Fla. July 21, 2023) (ECF No. 1177).
[61] *See United States v. Fla.*, No. 12-CV-60460, 2023 WL 4763189 (S.D. Fla. July 25, 2023).

month later, Florida filed a motion to the Eleventh Circuit for a stay pending appeal, which has not been decided.[62] The Eleventh Circuit has, however, expedited the appeal.[63]

Some of the main issues on appeal are:

(1) whether the District Court properly considered the United States' *Olmstead* claim by:
   (a) evaluating the appropriateness of community placement for the 140 institutionalized children without examining each specific home,
   (b) evaluating families' non-opposition to community placement by looking at whether they would accept community-based services "if they were actually available and accessible" rather than applying present-day circumstances, and
   (c) finding the proposed modifications reasonable (Florida also argued that it did not have sufficient notice of the injunction requirements to prepare a fundamental-alteration defense);[64]
(2) whether the District Court acted in its discretion to issue an injunction, holding a serious risk of institutionalization is actionable, respecting federalism principles, and determining that Florida can meet a 90% benchmark;[65] and
(3) whether the United States has authority under the ADA to enforce the rights of all children affected by Florida's practices, or if it should be limited to children who have filed administrative complaints.[66]

The National Health Law Program and fourteen *amici* comprised of pediatric medical experts, professional medical associations, and public health, family, and disability advocacy organizations, filed an amicus brief in support of the United States and affirming the District Court's judgment.[67] The brief describes how professional literature supports the District Court's conclusion that Florida's practices violate the ADA. As noted in the brief, the literature echoes the record in showing that the family home is the most integrated and appropriate setting for children with MCCs under *Olmstead* and when public entities provide necessary support services, families of children with MCCs rarely oppose having their children live at home.[68]

Briefing for the appeal concludes on December 6, 2023, and oral argument is scheduled for the week of January 22, 2024.[69] We will post updates on the case as they develop.

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[62] Mot. to Stay Pending Appeal, *United States v. Fla.*, No. 23-12331 (11th Cir. Aug. 21, 2023) (ECF No. 16).
[63] *See* Order, *supra* note 2.
[64] *See* Florida App. Br. 18-38; United States Resp. Br. 14-37.
[65] *See* Florida App. Br. 38-51; United States Resp. Br. 37-57.
[66] *See* Florida App. Br. 51-53; United States Resp. Br. 57-60.
[67] Amicus Brief of Am. Acad. of Pediatrics et al., *United States v. Fla.*, No. 23-12331 (11th Cir. Nov. 15, 2023) (ECF No. 43).
[68] *Id.* at 9-24.
[69] *See* Order, *supra* note 2; Notice to Counsel, *supra* note 2.