UNITED STATES DISTRICT COURT
SOUTHERN DISTRICT OF FLORIDA

Case No. 12-cv-60460-MIDDLEBROOKS/Hunt

UNITED STATES OF AMERICA

Plaintiff,

vs.

STATE OF FLORIDA,

Defendant.
_______________________________________/

MEMORANDUM OPINION AND ORDER

> *"…while at [Kidz Korner], my depression got so bad that I wanted to fall asleep and not wake up. But since being at home, it hasn't been like that."*[1]

Jade Quinones is 19, and for four years she resided at The Kidz Korner ("Kidz Korner"), a pediatric nursing home in Plantation, Florida, one of three such facilities in the state. She has complex medical needs, requiring the use of life-sustaining medical equipment. She is confined to a wheelchair, and she breathes with the assistance of a tracheal tube ("trach") and ventilator. She has suffered hearing loss, and she communicates by means of a tablet. But she is an enthusiastic reader, and she aspires to be an author. "I want to be a romance author because there's so many things you can experience and create. I mean, what is not to love about love?" (DE 789-25 at 18).

Jade described the loneliness and isolation she experienced at Kidz Korner, the time it took for her soiled clothing to be changed, and the fear and panic she felt when her trach became dislodged and she waited for someone to help, because without it she cannot breathe. She is now happy at home and feels safer with her parents and sister taking care of her.

Her mother described the difficulties she faced in bringing Jade home. During trial, parent after parent spoke of their desperation in trying to unite their family and bring their child with medical complexity home. Confusing and inconsistent discharge requirements and Care Coordination, delays in obtaining necessary equipment, and most significantly, limited access to prescribed private duty nursing presented a maze almost impossible for parents to escape.

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[1] Quoted from the deposition testimony of Jade Quinones, which can be found at DE 789-25. Excerpts from Jade's videotaped deposition were played during the bench trial. This quote can be found at page 22.

This should not have happened. Unjustified isolation is properly regarded as discrimination based on disability. *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 597 (1999). Over thirty years ago, on July 26, 1990, President George H.W. Bush signed the Americans with Disabilities Act to signal "the end to the unjustified segregation and exclusion of persons with disabilities from the mainstream of American life." *Transcript of Statement by the President, July 26, 1990*, National Archives.[2] Nonetheless, the State is violating the rights of children with medical complexity who rely upon the provision of vital Medicaid services and are trying, in vain, to avoid growing up in nursing homes.

Unjustified institutionalization of individuals with disabilities is unacceptable, especially given the advances in technology and in the provision of home-based care. Any family who wants to care for their child at home should be able to do so.

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[2] Available at https://www.archives.gov/research/americans-with-disabilities/transcriptions/naid-6037493-statement-by-the-president-americans-with-disabilities-act-of-1990.html.

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I. INTRODUCTION

A. Overview of the Case

The children at issue here are under 21 years old and have disabilities resulting in their need for medical services on a daily basis. As such, the children often qualify for Medicaid and require help conducting activities of daily living. Necessary services include: the use of technology or equipment for communication, mobility, breathing, eating, and other tasks, as well as the use and maintenance of feeding tubes, breathing tubes, ventilators, and wheelchairs.

Those who are institutionalized are spending months, and sometimes years of their youth isolated from family and the outside world. They don't need to be there. I am convinced of this after listening to the evidence, hearing from the experts, and touring one of these facilities myself. If provided adequate services, most of these children could thrive in their own homes, nurtured by their own families. Or if not at home, then in some other community-based setting that would support their psychological and emotional health, while also attending to their physical needs.

The United States filed this lawsuit against the State of Florida in 2013. The suit was brought on behalf of hundreds of children described as "medically fragile" or "medically complex." *See United States v. Florida*, Case No. 13-61576-CV-Dimitrouleas, DE 1 at 4.[3] Some reside in pediatric nursing facilities ("Institutionalized Children"), and others reside in the community but are at serious risk of institutionalization due to lack of access to necessary services ("At-Risk Children"). There are approximately 140 Institutionalized Children. The number of At-Risk Children totals more than 1,800.

It has taken over a decade for this case to finally reach trial. But today, I conclude that the United States met its burden of proving that the State of Florida is administering its services in a way that discriminates against children with disabilities, in violation of Title II of the Americans with Disabilities Act ("ADA"), 42 U.S.C. §§ 12131-12134. The State of Florida must remedy this problem and must do so immediately.

B. The Bench Trial

The ADA prohibits discrimination against individuals with disabilities, including Medicaid recipients. The government's one-count Amended Complaint alleges that the state discriminates against children with medical complexity who require long-term care by failing to administer its services in the most integrated setting appropriate to their needs. (DE 700). The United States seeks injunctive relief. (*Id.*)

The trial spanned two weeks. Those who testified were family members, renowned medical doctors specializing in pediatrics for kids with medical complexity, nursing facility staff, experts in Medicaid policy, and representatives from various State agencies, among other witnesses. In addition, both sides introduced a staggering number of exhibits consisting of thousands of pages of documents.

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[3] This complaint does not appear in the instant consolidated docket. It was filed under the original case number prior to the consolidation order. (Case No. 13-61576-CV-Dimitrouleas, at DE 1).

Several dominant themes emerged during the course of the bench trial. Most notable was the intensity of the experiences described by the families. I heard heroic stories of parents' commitment to their children as they struggled to manage for their care despite critical lapses in necessary services. Another component of the trial was a robust battle of experts, both sides having elicited opinions from highly accomplished pediatricians, researchers, and policy advisors.

Several Medicaid services were put at issue, but there is little question that the shortfalls in meeting the need for private duty nursing (or "PDN") was at the heart of this case – the subject was addressed by nearly every witness who took the stand. The lack of access to PDN was by far the most glaring and critical problem facing families with medically complex children. Most families are receiving nowhere near the number of hours they require. And the State's remarkably inadequate system of data collection renders it unable to even meaningfully diagnose the problem, much less solve it. This, combined with the unwieldy manner in which Florida administers its Medicaid program (involving a complicated web of various state agencies, private companies, and other stakeholders) has resulted in a stark lack of accountability. By the close of the evidence, I was convinced that the deficit of PDN in Florida is causing systemic institutionalization.

The other services highlighted at trial were: (1) the State's iBudget waiver program, which is a way for families to acquire non-medical services to support community placement, and for which families spend years on waitlists; (2) Care Coordination, a service whereby managed care plans facilitate the ability of families to care for their kids at home if they so choose, but families are simply not being informed about alternatives to institutionalization, nor are their Care Coordinators helping them navigate the system effectively; and (3) Medical Foster Care, which provides community-based placement in residential settings for medically complex kids who qualify, but eligible kids linger in nursing homes without being matched with a foster family.

In short, I heard overwhelming evidence of Florida's failings in administering these services. I will set forth my findings and conclusions regarding each of these issues below, and I will close by setting the stage for solutions – the remedy.

II. THE ADA AND *OLMSTEAD*

A. Statutory Language and Purpose

Title II of the ADA provides that "'qualified individual[s] with a disability' may not 'be subjected to discrimination.'" *Olmstead*, 527 U.S. at 602 (quoting 42 U.S.C. § 12132).[4]

The ADA was enacted to "provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities" and "to provide clear, strong, consistent, enforceable standards addressing discrimination against individuals with disabilities[.]" 42 U.S.C. § 12101(b)(1)-(2). This "broad mandate" of "comprehensive character" has a "sweeping

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[4] An individual has a "disability" under the ADA if they have a "physical or mental impairment that substantially limits one or more major life activities of such individual[.]" 42 U.S.C. § 12102(1)(A). Major life activities include, but are not limited to, caring for oneself, seeing, hearing, walking, speaking, breathing, learning, reading, and communicating, as well as the operation of a major bodily function, including, but not limited to, functions of the immune system, digestive, bowel, bladder, neurological, brain, and respiratory functions. *Id.* § 12102(2).

purpose," which is to "eliminate discrimination against disabled individuals, and to integrate them into the economic and social mainstream of American life." *PGA Tour, Inc. v. Martin*, 532 U.S. 661, 675 (2001) (quotation marks and citation omitted).

In statutory findings, Congress recognized 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). Noting that discrimination "persists in such critical areas as . . . institutionalization, health services, . . . and access to public services," Congress explicitly classified "segregation" as one such form of discrimination. 42 U.S.C. §§ 12101(a)(3), 12101(a)(5).

Title II of the ADA prohibits disability discrimination by state and local governments including Defendant, the State of Florida. 42 U.S.C. §§ 12132, 12131(1)(A); DE 840 (Pretrial Stipulation), Section VIII (Issues of Law on Which There Is Agreement), ¶ 7. Sections 12131-12134 of the ADA address public services provided by public entities and provide that "no qualified individual with a disability 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.

B. The Integration Mandate and *Olmstead*

This case is governed by the Supreme Court's decision in *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581 (1999), which concerned two voluntarily institutionalized patients in state-run institutions in Georgia. *Id.* The women brought suit for injunctive relief against Georgia officials alleging a Title II violation due to Georgia's failure to place them in a community-based program despite a finding by their treating physicians that such placement was appropriate. *Id.* at 593-94. The Supreme Court held that Title II prohibits "undue institutionalization" as a form of disability discrimination by state and local governments. *Id.* at 597. Such discrimination is effectuated by the manner in which public entities administer their services and programs, requiring people with disabilities "[to] relinquish participation in community life they could enjoy given reasonable modifications." *Id.* at 601. As one district court observed, "the alleged discrimination – undue isolation – stems from a failure to satisfy an affirmative duty." *Guggenberger v. Minnesota*, 198 F. Supp. 3d 973, 1032 (D. Minn. 2016).

To avoid this form of discrimination, the integration mandate of the ADA affirmatively requires state and local governments to "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). The "most integrated setting appropriate" is the "setting that enables individuals with disabilities to interact with nondisabled persons to the fullest extent possible[.]" 28 C.F.R. pt. 35, App. B at 703 (2021).

The Supreme Court explained that its holding "reflects two evident judgments." *Olmstead*, 527 U.S. at 600. First, "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life." *Id.* Second, "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 (citation omitted).

Under *Olmstead*, the State is required to provide disability services to children in the community, instead of in nursing facilities, when three conditions are met: (1) "the State's treatment professionals have determined that 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 mental disabilities." *Id.* at 587, 607; 42 U.S.C. § 12132. If the State's administration of a program discriminates against disabled individuals, then the remedy is to modify the program, unless the State can prove that such modification would fundamentally alter the program. *Olmstead*, at 592 (citing 28 C.F.R. § 35.130(b)(7)).

Causation is *not* an element of an *Olmstead* case. The State is required to provide treatment options in the community if the three elements are met. Indeed, "[s]omewhat unusually, the ADA 'impose[s] upon public entities *an affirmative obligation* to make reasonable accommodations for disabled individuals. Where a defendant fails to meet this affirmative obligation, the cause of that failure is *irrelevant*.'" *United States v. Mississippi*, 400 F. Supp. 3d 546, 554 (S.D. Miss. 2019) (original emphasis) (quoting *Bennett-Nelson v. Louisiana Bd. of Regents*, 431 F.3d 448, 454-55 (5th Cir. 2005)).

States cannot avoid *Olmstead* liability by contracting away their duty to provide services. In other words, States may not discriminate indirectly more than they may do so directly. *See* 28 C.F.R. § 35.130(b)(1), (3) (public entities may not discriminate "directly or through contractual . . . or other arrangements"). *See also Price v. Shibinette*, No. 21-cv-25, 2021 WL 5397864, at *9-10 (D.N.H. Nov. 18, 2021) (explaining that states cannot avoid liability under the integration mandate by "contracting out to private entities their obligation to provide services in compliance with the ADA[.]"); *Parrales*, 2015 WL 13373978, at *4 (rejecting Florida's traceability argument that any failings in delivery of services were the fault of managed care organizations, because Florida was responsible for administering program, and finding harms that flow indirectly from the state's action can establish traceability); *see also Disability Advocates, Inc. v. Paterson* ("*DAI I*"), 598 F. Supp. 2d 289, 316-19 (E.D.N.Y. 2009) (finding a state's planning, funding, and administration of service system sufficient to confer liability where state services were provided through private entities); *Conn. Office of Prot. & Advocacy for Persons with Disabilities v. Connecticut*, 706 F. Supp. 2d 266, 276-77 (D. Conn. 2010); *Joseph S. v. Hogan*, 561 F. Supp. 2d 280, 286-87, 293 (E.D.N.Y. 2008); *Long v. Benson*, No. 4:08-cv-26, 2008 WL 4571904, at *3 (N.D. Fla. Oct. 14, 2008).

C. Olmstead Applies to At-Risk Children

The *Olmstead* ruling has been found to cover both institutionalized individuals as well as those who are at serious risk of institutional placement. Every court of appeals to have addressed the issue has held as much, beginning with the Tenth Circuit in 2003. *See Waskul v. Washtenaw Cty. Cmty. Mental Health*, 979 F.3d 426, 460-62 (6th Cir. 2020); *Steimel v. Wernert*, 823 F.3d 902, 911-12 (7th Cir. 2016); *Davis v. Shah*, 821 F.3d 231, 262-64 (2d Cir. 2016); *Pashby v. Delia*, 709 F.3d 307, 322 (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).

This makes sense, because the integration mandate of the ADA "would be meaningless if [people with disabilities] were required to segregate themselves by entering an institution before they could challenge an allegedly discriminatory law or policy that threatens to force them into segregated isolation." *Fisher v. Okla. Health Care Auth*., 335 F.3d 1175, 1181 (10th Cir. 2003).

Thus, "[a] State's program violates the ADA's integration mandate if it creates the risk of segregation; neither present nor inevitable segregation is required." *Pitts v. Greenstein*, No. 10-635-JJB-SR, 2011 WL 1897552, at *3 (M.D. La. May 18, 2011) (emphasis omitted). I agree that something more than just "a generalized fear of institutionalization" is required in order to establish that a category of persons is at risk of institutional placement due to the insufficient provision of needed services. *See Parrales v. Dudek*, No. 4:15-cv-424, 2015 WL 13373978, at *5 (N.D. Fla. Dec. 24, 2015). A serious risk of unnecessary segregation is shown where the failure to provide community-based services will likely cause a decline in health, safety, or welfare leading to eventual institutional placement. *See*, *e.g.*, *Davis*, 821 F.3d at 263-64.

III. PROCEDURAL HISTORY

This case has taken a unique and protracted procedural path, particularly noteworthy for the length of time it has been pending. That it took 9 years and 9 months before finally culminating in the bench trial over which I presided is a failure of the judicial system, and it is the children who have suffered from this delay.

The case has traversed the dockets of three district court judges over the past decade. One of those judges, upon deciding that he disagreed with a case-dispositive issue previously adjudicated by his predecessor, *sua sponte* dismissed the action three years after it was filed. *C.V. v. Dudek*, 209 F. Supp. 3d 1279, 1282 (S.D. Fla. 2016). An appeal followed. Indeed, this litigation has resulted in the publication of two Eleventh Circuit opinions, and dissenting opinions, before even reaching the trial phase.

The children involved are among society's most vulnerable. Tragically, three of the named plaintiffs in the related class action lawsuit, T.F., A.C., and L.J., died while the case was pending.[5] Thus, the need for swift action to remedy the State's discriminatory conduct cannot be more clear.

The procedural history has been complex. I'll endeavor now to set out what has transpired to date.

A. <u>Consolidation of Cases: The Children's Class Action and the United States' Enforcement Action</u>

This is actually the last remaining of several disability discrimination cases against Florida that have been filed and subsequently consolidated.[6] Initially, two putative class action lawsuits

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[5] T.F. died on April 6, 2013. A.C. died on July 21, 2014. L.J. died on December 30, 2013. (DEs 147, 149, 245, 260, 518).

[6] And even before this series of cases, other *Olmstead* complaints were being filed by individual children, alleging violations of the ADA and other claims aimed at acquiring needed Medicaid

were filed on the same date, March 13, 2012. One was brought by a group of institutionalized children (Case No. 12-60461-CV-Dimitrouleas), and the other was brought by a group of children who were at risk of nursing facility placement (Case No. 12-60460-Zloch). All of the children involved were diagnosed as "medically fragile" and qualified for services through Medicaid. Both lawsuits alleged violations of the ADA, among other claims.[7] The Defendants were State of Florida agency heads as well as eQHealth Solutions, Inc., a corporation that contracted with the State to provide prior authorization of home health services. These cases were consolidated with Judge William J. Zloch who was assigned the first filed case. (DE 24, May 11, 2012). Thereafter, the Plaintiffs filed a single Consolidated Amended Complaint, naming both the Institutionalized Children and the At-Risk Children (hereafter "Children's Class Action"). (DE 29, May 16, 2012) (Second Amended Complaint filed August 23, 2012 (DE 62)). Two months later, on July 17, 2012, the case was reassigned to then-District Judge Robin S. Rosenbaum.[8]

At the inception of the Children's Class Action case, there were a total of eight children who were named as Plaintiffs. They were represented by a disability law group. But throughout the early stages of litigation, the United States kept chiming in with "Statements of Interest," filing substantive briefs opposing motions to dismiss, supporting Plaintiffs' motion for class

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services to support community living and avoid institutionalization. *See, e.g., Cruz v. Dudek*, No. 10-23048-CIV, 2010 WL 4284955 (S.D. Fla. Oct. 12, 2010) (granting motion for preliminary injunction requiring Florida's Agency for Health Care Administration ("AHCA") to provide the plaintiffs, who were Medicaid recipients at risk of nursing facility placement, with adequate home-based services to prevent their imminent institutionalization), *adopted by* Order Adopting Report & Recommendations, *Cruz v. Dudek*, No. 10-23048-CV-Ungaro, at DE 57 (S.D. Fla. Nov. 24, 2010). *See also Haddad v. Dudek*, 784 F. Supp. 2d 1308, 1317 (M.D. Fla. 2011) (denying motion to dismiss where plaintiff Medicaid recipient "alleged that denial of Medicaid funding for . . . community-based services . . . [and the] requirement conditioning receipt of [such] services on her entering a nursing home for sixty days against her will, constitute unlawful discrimination in violation of the ADA and the Rehab Act."). I note that the 2010 case before Judge Ungaro involved the State's administration of the Medicaid home-based care program, and plaintiffs' inability to access a sufficient number of hours from skilled and unskilled personnel to assist with activities of daily living. The case today echoes this same theme, 13 years later. This speaks to the need for broad vindication of the rights of this population of children by way of an Enforcement Action, like this.

[7] Additional claims included alleged violations of Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794; the Medicaid Act, 42 U.S.C. §§ 1396-1396v; the Nursing Home Reform Amendments to the Medicaid Act, 42 U.S.C. § 1396r; Early and Periodic Screening, Diagnostic, and Treatment Services, 42 U.S.C. § 1396d(r) provisions; and 42 U.S.C. § 1983. The Children's Class Action also sought a declaration by the Court that the State's and eQHealth's policies, regulations, actions, and omissions are unnecessarily institutionalizing members of the Plaintiff Class or putting Plaintiffs at risk of being placed into segregated facilities.

[8] The transfer to Judge Rosenbaum was in connection with a randomly assigned batch upon her appointment to the district court bench. (DE 47).

certification, and the like. (*See, e.g.* DE 45, DE 136).[9] This is because the United States too was preparing to file a lawsuit to vindicate the civil rights of this same population of children (hereafter "the Enforcement Action"), which is this case. That Enforcement Action, once filed, was eventually consolidated with the Children's Class Action in December of 2013. *See A.R. v. Sec'y Fla. Agency for Health Care Admin.*, 769 F. App'x 718 (11th Cir. 2019).

The Enforcement Action began with a six-month long investigation commenced by the Department of Justice in December of 2011. *United States v. Florida*, 938 F. 3d 1221, 1224 (11th Cir. 2019), *cert. denied*, 143 S. Ct. 89 (2022). The investigation was prompted by complaints of disability discrimination filed with the DOJ. (*See* DE 789-8 (filed under seal); DE 1165 at 28-30). In September of 2012, the United States issued a "Letter of Findings," notifying the State of Florida that it was unnecessarily segregating children with complex medical needs in nursing facilities and placing other children at serious risk of unnecessary segregation. *United States v. Florida*, 938 F.3d at 1224-25, *cert. denied*, 143 S. Ct. 89 (2022). Following attempts to obtain a resolution with the State, the United States determined that it could not obtain voluntary compliance and filed this lawsuit seeking declaratory and injunctive relief on July 22, 2013. *Id.* at 1225; *see United States v. Florida*, Case No. 13-61576-CV-Dimitrouleas at DE 1. The Enforcement Action was promptly transferred to Judge Rosenbaum as a related case. *See* Case No. 13-61576-CV-Rosenbaum at DE 10. And then on September 19, 2013, Judge Rosenbaum consolidated the case with the Children's Class Action, over the objection of the State of Florida. (DE 215).[10] From then on, all filings for both cases were made on the instant docket, in Case No. 12-60460.

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[9] The United States' first "Statement of Interest" was filed on June 28, 2012 and it stated: "The United States respectfully submits this Statement of Interest, pursuant to 28 U.S.C. § 517, because this litigation implicates the proper interpretation and application of the integration mandate of Title II of the [ADA], *See Olmstead v. L.C.*, 527 U.S. 581 (1999). The Attorney General has authority to enforce Title II of the ADA, and pursuant to Congressional mandate, to issue regulations setting forth the forms of discrimination prohibited by Title II. Accordingly, the United States has a strong interest in the resolution of this matter." (DE 45 (citations omitted)). The Statement of Interest was effectively a substantive response in opposition to the State Defendants' Motion to Dismiss the Amended Consolidated Complaint on Rule 12(b)(6) grounds (DE 32), which was later denied (DE 46). Subsequent Statements of Interest were filed by the United States in response to other filings. (*e.g.*, DEs 136, 212).

[10] Florida opposed consolidation, arguing that it would significantly broaden the matters at issue particularly given that the plaintiffs in the Children's Class Action had failed to get the class certified, and therefore the scope of that litigation would ultimately wind up being quite narrow, involving only nine children and their individualized remedies. But Judge Rosenbaum reasoned that the cases involved common, complex issues of fact, both centering around Plaintiffs' contentions that Defendants are unnecessarily segregating and institutionalizing children and "both lawsuits claim that Defendants have failed and continue to fail to provide medically necessary services in home and community-based settings to Medicaid-recipient children in Florida." (DE 215 at 11). Moreover, both cases sought declaratory and injunctive relief, seeking a declaration that Defendants were violating the ADA due to its policies, regulations, actions, and omissions. *Id.* at 11-12.

B. Turning Points in the Litigation

The Enforcement Action contains a single count against the State of Florida, alleging that Florida is unjustifiably segregating institutionalized children, and that it adopted policies and practices that place other children at serious risk of similar institutionalization, in violation of Title II of the ADA.

The issue of the United States' authority to sue was first raised on November 21, 2013, when the State of Florida filed a Motion for Judgment on the Pleadings. (DE 28).[11] Therein, the State argued that Congress has not authorized the Attorney General to sue under Title II of the ADA, and therefore the United States lacked standing. Judge Rosenbaum denied the motion on May 30, 2014. (DE 40 in Case No. 13-61576-CV-Rosenbaum). On that same date, the case was reassigned from Judge Rosenbaum back to Judge Zloch, pursuant to Administrative Order 2014-48. (DE 251). He set the trial for a date in 2016 (DE 373), and the case proceeded for two more years, through discovery and a series of rulings on multiple substantive pretrial motions. Then, as trial preparations were ramping up, Judge Zloch *sua sponte* revisited the question of the United States' authority to sue. On September 20, 2016, he entered an Order finding that the Attorney General lacked standing and dismissed the Enforcement Action. (DE 543).[12]

Meanwhile the Children's Class Action, which was the other half of this consolidated case, proceeded through litigation. The originally named plaintiffs were never able to get the class certified. The proposed class included "[a]ll current and future Medicaid recipients in Florida under the age of 21, who are (1) institutionalized in nursing facilities, or (2) medically complex or fragile and at risk of institutionalization in nursing facilities." (DE 329 at 2). The Court found that the proposed class was simply "too broad and over inclusive so as to be adequately defined." (DE 395 at 13; DE 448 at 2). Their original motion to certify, and two renewed motions after that, were all denied. (DE 95, DE 203; DE 395; DE 448). This meant that the Children's Class Action was actually a case for individualized relief, concerning the medical histories of only a handful of children. And the Enforcement Action – challenging the policies of the State and seeking systemic changes to the provision of Medicaid services to all affected children – was on hold, awaiting the United States' ability to appeal Judge Zloch's *sua sponte* dismissal.

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[11] This motion does not appear in the instant consolidated docket. It was filed under the original case number prior to the consolidation order. (Case No. 13-61576-CV-Rosenbaum at DE 28). However responses and replies to the motion *were* filed in the consolidated docket (DE 226; DE 230). Judge Rosenbaum's Order on the motion appears in the original docket (Case no. 13-61576-CV-Rosenbaum at DE 40).

[12] The United States was poised to appeal and moved the Court to undo the consolidation so that a final order could be entered. (DE 553). That motion was denied. (DE 560). So, the United States moved for entry of judgment, or in the alternative, certification of the order of dismissal for interlocutory review. (DE 586). That request too was denied. (DE 590). The United States was only able to pursue its appeal 11 months later, after the Children's Class Action was resolved on summary judgment. (DE 648).

C. Eventual Fate of the Children's Class Action, and Consequent Need for the Enforcement Action

The Class Action case was hard fought after the United States was dismissed. The Defendants repeatedly raised mootness challenges as certain plaintiffs "aged out" of Medicaid eligibility, moved away, died, or the State amended its administrative rules. The Plaintiffs filed renewed motions for class certification. There were multiple discovery disputes adjudicated by then-paired Magistrate Judge Patrick Hunt.[13] Ultimately, the Children's Class Action was resolved on summary judgment in favor of Defendants in June of 2017. (DE 634 (Judge Hunt's Report & Recommendations); DE 645 (order adopting)). By that time, there were only three named Plaintiffs remaining (C.V., M.D., and C.M.). The case was closed.

Then, on September 17, 2019, a divided panel of the Eleventh Circuit Court of Appeals published an opinion reversing Judge Zloch's *sua sponte* dismissal, finding that the Attorney General did indeed have authority to bring the Enforcement Action. *United States v. Fla.*, 938 F.3d 1221, 1250 (11th Cir. 2019). The State sought *en banc* review. On December 22, 2021, the court declined to take the case *en banc*, publishing an opinion and a dissent in connection with that decision. *United States v. Sec'y Fla. Agency for Health Care Admin.*, 21 F.4th 730 (11th Cir. 2021). The State of Florida filed a petition for certiorari in the United States Supreme Court, which was denied. (DE 731). *Fla. v. United States*, 143 S. Ct. 89 (2022). The mandate issued on January 11, 2022. (DE 666). The case was reopened.

D. Post-Remand through Bench Trial

With Judge Zloch in retirement, the case was reassigned to Judge Altonaga upon being reopened on January 12, 2022. (DE 667). She recused on January 20, 2022, and I was assigned the case on the same day. (DE 675).

Florida sought a stay of discovery which I denied. The United States did not want to stay the case, but requested one-and-a-half years to conduct discovery, which I also denied. Instead, I held a scheduling conference on April 15, 2022, and set trial for May 8, 2023. (DEs 682, 685, 686).

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[13] Judge Hunt entered the scene in October of 2014 on a referral order for discovery motions (DE 277), and he remained the paired Magistrate Judge on the case for the next decade, including this past year since I have been the presiding judge. This has been a massive undertaking. Judge Hunt held 13 hearings totaling many hours in court. He drafted 10 Reports & Recommendations on complex substantive motions, and he entered a total of 78 orders on the docket. At least 20 of these orders resolved various types of discovery disputes. Judge Hunt's work has been thorough and prompt. And throughout the litigation he has been highly responsive to the demands of the trial calendar. None of the delay in adjudicating this case is in any way attributable to him. Indeed, I credit Judge Hunt for my ability to conduct this trial on time, as it was his work in assisting with the resolution of cross motions for summary judgment that ensured the case was ready to proceed as scheduled. Judge Hunt's final contribution was to conduct a settlement conference the week before trial began, and that task spanned several days. In short, Judge Hunt is to be commended for his extraordinary work.

Active discovery ensued, fraught with disputes capably resolved by Magistrate Judge Hunt. After denying the State's Motion to Dismiss (DE 791), and after ruling on the Parties' cross motions for summary judgment (DE 882), and upon denying both sides' efforts to strike the other's expert witnesses (DE 861), the bench trial finally commenced as scheduled.

I repeatedly urged the Parties to resolve the case. Prior to the trial, I sent the case to Magistrate Judge Hunt for a settlement conference. At the close of evidence, I announced that I had tentatively decided to rule for the federal government and urged the Parties to either settle the case or agree on the terms of a remedy. I ordered both sides to brief the remedy issue. The State has refused to engage and has opposed every measure suggested by the United States.

IV. STANDING

As a threshold issue, I will first address the State's longstanding contention that this case should never have been filed. The State raises several challenges premised upon standing, all of which fail. I will take each in turn.

A. Authority to Sue

First, the State argues that the United States does not have standing to maintain this action under Title II of the ADA, 42 U.S.C. § 12133, because its authority to sue is limited (in its telling) to vindicating the rights of individual complainants. The State points out that only one child (C.M.) ever filed an administrative complaint and his claims (as part of the putative class action) were denied as moot by this Court. (DE 868 at 61) (citing *A.R. v. Sec'y Fla. Agency for Health Care Admin.*, 769 F. App'x 718 (11th Cir. 2019) (affirming dismissal of putative class action's claims on mootness grounds)). Essentially then, under the State's reasoning, the United States' authority to proceed in this action extinguished in 2019.

The fatal flaw in the State's argument is that only five months after the Eleventh Circuit decided *A.R. v. Sec'y Fla. Agency,* it held – based on the same underlying facts – that the United States has authority to proceed in this very action. *United States v. Fla.*, 938 F.3d 1221, 1250 (11th Cir. 2019) ("Florida may have valid complaints about this lawsuit, but whether it is amenable to suit by the United States is not one of them."). And in 2021, the Eleventh Circuit denied rehearing en banc its panel's 2019 decision. *United States v. Sec'y Fla. Agency for Health Care Admin.*, 21 F.4th 730 (11th Cir. 2021) (J. Pryor, J., respecting the denial of rehearing en banc) ("[T]he panel correctly held that the Attorney General was authorized in this case to sue the State of Florida, on behalf of the medically-fragile children, for disability discrimination."). The only way for the State's argument to make any sense is to make the assumption that the Eleventh Circuit simply overlooked this issue – twice. As unlikely as that sounds, the State seems to actually argue that. (*See* DE 868 at 61) ("To permit the United States to parlay one complaint—which has been resolved—into this enforcement action to enforce the purported rights of more than 100 children who never invoked its aid would expand the United States' authority far beyond the Eleventh Circuit's reasoning."). I do not see how the State's position is anything but a repackaging of an issue already decided by the Eleventh Circuit.

Even assuming that *United States v. Fla.* is somehow not controlling, the State's theory of how § 12133 works fails on its own terms because it is completely unworkable and diverges from how the enforcement statutes on which § 12133 relies function. After C.M.'s administrative complaint, and several other informal complaints (DE 1165 at 28-30), the United States initiated an investigation into the State's system for delivering services to medically complex children. (DOJ Letter of Finding, DE 291-1). As part of the investigation, DOJ visited "six large nursing facilities[,] . . . . met with numerous children and received a substantial amount of data." (*Id*. at 3). In its Letter of Finding, DOJ identified the same failings that this case is predicated on today and gave the State an opportunity to voluntarily cure those problems. (*Id*. at 23). Not then, and not now, has the State been willing to do so.

Instead – consistent with the State's longstanding litigation strategy to try to moot out this case at every turn – it proposes a hamster wheel theory of § 12133, whereby the United States must restart litigation every time a child ages out of the system or, as is so unfortunately common, dies. Surely Congress did not intend for such a burdensome enforcement scheme when it "envisioned that, through the ADA, the federal government would take 'a central role in enforcing the standards established in this chapter on behalf of individuals with disabilities,' and invoked 'the sweep of congressional authority, including the power to enforce the [F]ourteenth [A]mendment and to regulate commerce' to 'address the major areas of discrimination faced day-to-day by people with disabilities.'" *United States v. Fla.*, 938 F.3d at 1226 (citation omitted). As a corollary to the State's theory, the United States would also be in the untenable position of basically functioning as the individual complainant's lawyer. (*See* DE 910 at 245) (State questioning United States' corporate representative regarding whether "any parents or guardians of the children whom the United States has identified [as raising informal complaints] . . . asked the United States to bring or maintain this action to enforce their children's rights?").

The State's theory is also inconsistent with enforcement actions under the Rehabilitation Act, which § 12133 incorporates by reference as its own scheme. *See United States v. Fla.*, 938 F.3d at 1236-37 (citing *United States v. Bd. of Trustees for Univ. of Ala.*, 908 F.2d 740, 742 (11th Cir. 1990)). In *Bd. of Trustees for Univ. of Ala.*, the United States brought an enforcement action "upon receipt of a complaint by a deaf student whose request for services of a sign language interpreter at UAB's expense was initially denied." 908 F.2d at 742. Notwithstanding the limited nature of the administrative complaint, the United States' enforcement action encompassed violations involving swimming pool and bus transportation accessibility for mobility-impaired students. *Id*. at 743.

Lastly, the Supreme Court's interpretation of an analogous enforcement scheme – § 706(f)(1) of Title VII, as amended, 42 U.S.C.§ 2000e-5(f)(1), of the Civil Rights Act of 1964 – further undermines the State's constrained view. *See Gen. Tel. Co. of the N.W., Inc. v. Equal Empl. Opportunity Comm'n*, 446 U.S. 318 (1980). Much like here, § 706(f)(1) authorizes the Equal Employment Opportunity Commission ("EEOC") to sue employers if, after the filing of an administrative complaint, it cannot secure voluntary compliance. 42 U.S.C. § 2000e-5(f)(1). In *Gen. Tel.*, the Supreme Court faced the question of whether the EEOC may seek class wide relief under § 706(f)(1) without being certified as the class representative under Fed. R. Civ. P. 23. 446 U.S. at 320. The Court held that the EEOC did not have to comply with Rule 23 because, *inter alia*, its "enforcement actions are not limited to the claims presented by the charging parties. Any violations that the EEOC ascertains in the course of a reasonable investigation of the charging party's complaint are actionable." *Id*. at 331. That made sense, the Court reasoned, because – just like under Title II – the complainant could still bring their own civil action, suggesting that the EEOC is not "merely a proxy for the victims of discrimination . . . . " *Id*. at 326.

Accordingly, I find no merit in the State's statutory authority argument.

B. Traceability and Redressability

Separately, the State argues that the United States does not have constitutional standing because it has failed to prove traceability and redressability. To the extent the State argues that the United States fails to establish injury in fact, I dismiss that argument. (*See* Part VIII).

Under Article III of the United States Constitution, federal courts may only decide "Cases" and "Controversies." U.S. Const. art. III, § 2. To have standing, "[t]he plaintiff must have (1) suffered an injury in fact, (2) that is fairly traceable to the challenged conduct of the defendant, and (3) that is likely to be redressed by a favorable judicial decision." *Spokeo, Inc. v. Robins*, 578 U.S. 330, 38-39 (2016) (citing *Lujan v. Defs. of Wildlife*, 504 U.S. 555, 560-61 (1992)). Traceability is "something less than the concept of proximate cause." *Focus on the Family v. Pinellas Suncoast Transit Auth.*, 344 F.3d 1263, 1273 (11th Cir. 2003). In this posture, the United States must demonstrate that standing is "supported adequately by the evidence adduced at trial." *Lujan*, 504 U.S. at 561 (citation omitted).

Redressability is not all or nothing. *See Lewis v. Gov. of Alabama*, 944 F.3d 1287, 1301 (11th Cir. 2019) (cleaned up) ("[W]e ask whether a decision in plaintiff's favor would 'significantly increase the likelihood' that she 'would obtain relief that directly redresses the injury . . . .'"). However, "[w]here traceability and redressability depend on the conduct of a third party not before the court, 'standing is not precluded, but it is ordinarily substantially more difficult to establish.'" *Competitive Enter. Inst. v. Fed. Commc'ns Comm'n*, 970 F.3d 372, 381 (D.C. Cir. 2020) (citing *Lujan*, 504 U.S. at 562); *see also Lewis*, 944 F.3d at 1301 ("[I]t must be the effect of the court's judgment on the defendant – not an absent third party – that redresses the plaintiff's injury, whether directly or indirectly.") (emphasis and internal quotations omitted). "A permissible theory of standing 'does not rest on mere speculation about the decisions of third parties; it relies instead on the predictable effect of Government action on the decisions of third parties.'" *Competitive Enter.*, 970 F.3d at 381 (citing *Dep't of Com. v. New York*, 139 S.Ct. 2551, 2566 (2019)).

This burden can be – and indeed regularly is – overcome by plaintiffs that present sufficient evidence of a predictable effect on the decisions of third parties. *See, e.g.*, *Dep't of Com.*, 139 S.Ct. at 2566 (emphasis added) (finding traceability because "evidence at trial established that noncitizen households have historically responded to the census at lower rates than other groups, and the District Court did not clearly err in crediting the Census Bureau's theory that the discrepancy is likely attributable *at least in part* to noncitizens' reluctance to answer a citizenship question") (emphasis added); *Made in the USA Found. v. United States*, 242 F.3d 1300, 1307 (11th Cir. 2001) (same because "appellants [] amassed considerable evidence . . . from which we may infer that U.S. reimposition of tariff and non-tariff barriers to trade is by itself likely to result in somewhat reduced competition from foreign imports, thereby generating more demand for domestic production—and therefore more jobs, higher wages, and increased bargaining power—in the industries represented by the appellant labor organizations"). As is relevant here, courts may consider "arguments 'firmly rooted in the basic laws of economics'" to determine the "likely reaction of third parties." *Competitive Enter.*, 970 F.3d at 381-82 (collecting cases finding redressability based largely on logical predictions of market reactions).

The State hangs its hat on the fact that the relief sought by the United States will depend, in part, on the actions of third parties; *e.g.*, managed care plans and nursing agencies. For instance, the State concedes that there is a nursing shortage, but it disputes that this problem can be solved by paying nurses more, which is one of the solutions the United States proposes. As another example, the State argues that there is no modification to the State's Care Coordination program that will redress any single child's alleged unlawful institutionalization.

As an initial matter, I reject the State's underlying premise that the standing analysis should strictly follow the more stringent "third party action" doctrine. As hard as the State tries to distance itself from the actions of the managed care plans and nursing agencies, it is the State that is choosing to comply with Title II of the ADA through contracted entities. *See Parrales v. Dudek*, No. 15CV424, 2015 WL 13373978, at *4 (N.D. Fla. Dec. 24, 2015) (rejecting Florida's same argument and granting standing to plaintiffs). It would defy all logic if by doing so the State can then exempt itself from Title II of the ADA. The State's reasoning risks rendering *Olmstead* a dead letter.

In any event, the United States presented sufficient evidence at trial that enjoining the State would have a predictable effect on the decisions of third parties. For one, as I will later explain, the State's contracts with the managed care plans are extremely detailed and demanding – requiring 100% delivery of services. In one striking example, the State's contract details how fast phone inquiries must be responded to. So, when the State argues that redressability "depends on the unfettered choices made by independent actors not before the courts and whose exercise of broad and legitimate discretion the courts cannot presume either to control or to predict," I do not see how that is at all the case here. (DE 868 at 38) (citing *ASARCO Inc. v. Kadish*, 490 U.S. 605, 615 (1989)).

As to PDN specifically, the Court heard credible testimony that – not surprisingly – increasing nurses' pay would result in more available nurses to serve the needs of families caring for medically complex children. (*See* Testimony of RN Coordinator Kelsey Koehler, DE 908 at 113) ("[A]s soon as we started offering more money, the shifts would start to be covered."); (Testimony of Humana Care Manager Pamela Buchanan, DE 899 at 115-116) (identifying low pay as a major obstacle). Furthermore, as I will explain, the United States' cross examination of the State's expert on this issue showed that his opinion was misleading, and, if anything, proved that Florida's PDN reimbursement rates are remarkably low compared to other states. (*See* Cross Examination of Mr. Jessee, DE 897, 912). Dr. Letourneau, an assistant professor at South Florida College of Nursing, testified for the State that increasing nurses' pay is likely to attract nurses from other organizations, but that alone would not fix the nursing shortage. (Testimony of Dr. Letourneau, DE 912). To do so, Dr. Letourneau suggested beginning outreach in elementary schools and increasing recruiting into the teaching profession. Fair enough. But the United States does not have to demonstrate that increasing nurses' pay would solve the national nursing shortage, only that it would "significantly increase the likelihood" of more available PDN to children with medical complexity. *See Lewis v. Gov. of Alabama*, 944 F.3d at 1301 (11th Cir. 2019). In my view, Dr. Letourneau's testimony supported that conclusion.[14] This is the sort of evidence rooted in the

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[14] I find *Disability Rts. Fla., Inc. v. Palmer*, No. 18CV342, 2019 WL 11253085 (N.D. Fla. Aug. 29, 2019), a case relied on by the State, to be distinguishable. In *Disability Rts.*, the district court granted summary judgment on plaintiff's claim that Florida violated Title II by failing to ensure enough behavior analysts were available to serve individuals in rural areas under the iBudget waiver. *Id.* at *6. There, the court held that the plaintiff lacked Article III standing because causation was speculative and redressability absent. The court reasoned that causation was speculative because the "difficulty faced by consumers of behavior-analyst services in rural areas

basic laws of economics that courts regularly rely on. *See Made in the USA Found.*, 242 F.3d at 1307; *Competitive Enter.*, 970 F.3d at 381-82.[15]

I find the State's standing arguments outside of the PDN context, and in particular as applied to Care Coordination, to be misguided. The State argues that each modification must essentially be a silver bullet that results in a particular child going home. (*See* State's Closing Argument, DE 1165 at 97-98) ("We don't know to this day if we pick any provision out of their proposed injunction, and we say let's implement that, we don't know that there is a single child that would come out of a nursing facility."). The primary problem with that analysis is that to establish redressability, a plaintiff only has to show that a favorable decision would "'significantly increase the likelihood' that she 'would obtain relief that directly redresses the injury'"—not that it be a silver bullet. *Lewis*, 944 F.3d at 1301 (citation omitted). The evidence at trial certainly proved that poor Care Coordination was a true impediment to children going home. For example, the evidence showed that the families were not well-informed of alternatives to institutionalization, and even those who were informed nevertheless faced significant barriers in the form of disorganization and arbitrary requirements. (*See* Testimony of Mr. Amore and Ms. Newton, DE 906). Second, the State's attempt to isolate each modification in this manner ignores the reality that the children are institutionalized or at serious risk of being so because of a combination of the State's systemic failings, which the United States seeks to change.

V. FAMILY NARRATIVES

At the bench trial, I heard testimony from many affected families. The experiences of Caden, Josiah, Olivia, Carena and Jeffrey, summarized below, exemplify the types of issues faced by a large number of families caring for children with medical complexity. I also heard from the parents or caregivers of Jamiah, Dondrea, Dalton, Christian, and others, including many family witnesses for the State.[16] I can't tell every story, but throughout this Order I will refer to the examples of these children and others, as I explain how Florida's programs have failed them.

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is typical of difficulties across a range of products and services; consumers of products and services have fewer choices in rural areas." *Id*. at *7. And redressability was absent because the defendant in that case, the Director of the Florida Agency for Persons with Disabilities, did not have the ability to set reimbursement rates, AHCA does. *Id*. Here, Dr. Bachman persuasively testified that there is no difference in PDN hours received based on whether children resided in rural or urban counties. (Testimony of Dr. Bachman, DE 909). And nobody disputes that the State of Florida can change reimbursement rates.

[15] At trial, the State heavily criticized the United States for failing to present the testimony of a health care economist. However, the State does not cite to, and I could not identify, caselaw that requires a plaintiff to present its economic evidence through an economist. In my view, this simply goes to the weight of the evidence.

[16] I note that some parents and/or caregivers who testified on behalf of the State were apparently led to believe that through this lawsuit, the government was seeking to shut down pediatric nursing facilities. (*See* Testimony of Beatrice Soliz, DE 894 at 48: "I believe they are trying to close the place down" (referring to Kidz Korner, where her grandchild lives); Testimony of Shawana Williams, DE 894 at 29: "[This is] a case against centers like Kidz Korner to have them closed."; Testimony of Jeffrey Keys, DE 894 at 65-66: who said he needed to "represent Emily," his

Caden, Age 9

Three months after giving birth to Caden, his mother, suffering from a psychosis that was induced by her post-partum depression, threw him into a lake.[17] She took her own life six months later. Caden survived, but the near drowning resulted in anoxic brain injury. After his hospitalization and several surgeries as a young infant, he was released to a pediatric nursing facility – Kidz Korner, located in Plantation, Florida. His father did not know he had any other options.

Caden cannot speak and uses a wheelchair. He also relies upon a feeding tube for nutrition. Caden is now ventilator dependent, but he did not enter Kidz Korner that way. He contracted pneumonia while institutionalized and only thereafter did he require help breathing.

Mr. Amore described the process whereby he selected Kidz Korner as Caden's placement. He "sat down with some social workers and a couple of doctors in, like, a room at the hospital," and they proceeded to explain all of Caden's upcoming needs for medical care and extensive therapies, and then they listed Caden's many limitations. (DE 906 at 41). They told him he had a choice of two nursing homes, and he chose Kidz Korner after visiting both, because it was closer to his home at the time, and also a friend of his from church worked there. Caden ended up living in that facility for nearly his entire life. He is 9 now.

Before Caden was transitioned home (which happened during the pendency of this bench trial, as I'll explain below), Mr. Amore visited him at the nursing home almost every day. He managed this despite working long hours – 9:00 or 10:00 in the morning until 7:00 or 8:00 at night – at a job that requires him to stand. In the beginning, he was able to stay for several hours each

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institutionalized child with medical complexity, because he was concerned she "would get moved, and I don't want that.") It is unclear where these impressions came from. I found the testimony of these families to be truthful and credible, however the looming threat that they believed existed may have affected the way they described their experiences.

[17] The testimony of Mr. Amore, Caden's father, is available at DE 906, beginning on page 34.

visit. But after having other children, his visiting time became more limited, cut back to only about an hour and a half each day.

Mr. Amore testified about his relationship with his institutionalized child, and their typical routine. It was clear that Mr. Amore is a committed father and that Caden is attached to him. Dorothy Newton, Mr. Armore's fiancé, testified that when she first met Caden about five years ago, it was "kind of blissful to see the bond" shared by father and son.[18] (DE 906 at 77). They are "in tune," and Caden "is able to communicate with his dad without words." (*Id.* at 78).

Mr. Amore described Caden as a happy child. He smiles a lot. His eyes are bright. Although Caden is unable to talk, he communicates through facial expressions, especially when his father puts his face close to his and they rub noses. Caden cannot see very well, but he tries to mimic faces and noises. He enjoys being talked to, and he likes to watch cartoons and listen to music. He responds positively to the sight of family members and the familiar sounds of their voices, turning his head slightly in the direction of his loved ones. Caden and his father would read and listen to music together during Mr. Amore's visits at Kidz Korner.

Mr. Amore would go to the facility in the evenings and stay late. He regretted that he could only rarely take Caden outdoors, because it was already dark by the time he arrived after the work day. But on occasions when his father could get there early enough to take Caden out in the daytime, and Caden felt the sun on his skin, he was happy. In his room at the facility, which he shared with another child, Caden was often near the window so that he could "see outside and have that sunlight." (DE 906 at 79).

During visits, sometimes Caden's sister would come and she would climb into bed with him to bond. Mr. Amore would help Caden with stretching exercises, an activity Caden does not particularly like. He also learned to give Caden massages, which relaxed him and sometimes put him to sleep. Mr. Amore learned how to assist with Caden's speech therapies. And over time, Mr. Amore became adept at operating all of Caden's medical equipment independently.

When it came time for Mr. Amore to leave his son after these visits, Caden would sometimes become visibly upset, forcing air through his ventilator, causing it to emit a "high pressure" beep. (DE 906 at 47). It is clear when Caden is unhappy because he "grimaces." "He can also spike his own fever to tell you something is wrong." (*Id.* at 78).

Because of Caden's limited ability to communicate, Mr. Amore came up with a way to signal to Caden that their visitation time was winding down. Mr. Amore explained that from the earliest days, when Caden was a baby, he would "tap him three times on his head, three times on his chest, and three times on his leg." (DE 906 at 47, 81). They repeated this ritual each visit, with the goal of preparing Caden for the impending separation from his father. But if Caden became too distraught, Mr. Amore would just stay for another five minutes. With emotion in his voice, Mr. Amore testified that he never liked leaving Caden.

Ms. Newton visited Caden often also, anywhere from three to six times per week. Of Ms. Newton, Mr. Amore said: "she shows as much care and love for him as I do." (DE 906 at 53). She too became emotional when she described how Caden would sometimes cry when they had to say

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[18] Ms. Newton's testimony is available at DE 906, beginning on page 75.

goodbye. "[W]hat child wants to be left alone and not know when [his] parents are coming back?" (*Id.* at 82). "[I]t was very hard to leave him," she said. (*Id.* at 81-82).

Ms. Newton generally described her visits. Both she and Mr. Amore were active participants in Caden's care: "[W]e do his laundry." (DE 906 at 84). "[W]e assess his room and make sure that [he has] everything that he needs." (*Id.* at 79). She also described "helping with his therapies," "cleaning him up," and "[j]ust loving on him." (*Id.* at 79-80). Ms. Newton described her role as it pertained to Caden: "A mother, an advocate, a protector, a guardian." (*Id.* at 83). Indeed, Ms. Newton takes it upon herself to figure out what Caden's best options are, in terms of his support and treatments, to ensure that his life becomes increasingly "easier [and] better." (*Id.* at 83-84). She has raised issues and made suggestions to his doctors, which were eventually approved. Ms. Newton did not rely upon the Care Coordination team for such things, she was proactive, and Caden benefitted from her "legwork" and "behind-the-scenes research." (*Id.* at 83-84).

Throughout Caden's institutionalization, Mr. Amore signed "Freedom of Choice" forms. He only signed the forms because: "I didn't think I had any other options[.]" (DE 906 at 54). In connection with authorizing Caden's continued institutionalization, Mr. Amore said that he would participate in meetings. He described the process as being fairly non-informative and perfunctory. Mr. Amore would "talk on the phone with . . . Kidz Korner . . . [and] they pretty much say, hey, . . . 'Are you okay with leaving Caden at the skilled nursing facility?' And I [would] just say 'yes.'" (*Id.* at 55).

At monthly meetings, his Care Coordinator would mention "community-based options," but it was not clear what that meant. (DE 906 at 63). Mr. Amore recalls it being explained at one point as meaning "medical daycares[,] or something like that." (*Id.*). Regardless, the repeated, unexplained references to "community-based options" was unhelpful. "That doesn't sound like '*bring him home*' to me," Mr. Amore said. (*Id.*).

Only three or four years ago, when Ms. Newton started "digging," did the family realize that they could bring their child home. (DE 906 at 63). And after that, Mr. Amore expressed interest in transitioning Caden "more than a couple [of times] in the past," but he was deterred. (*Id.* at 54). As early as 2018, Ms. Newton began telling "anyone that would listen" that they wanted Caden out of Kidz Korner. (*Id.* at 85). In response, the family was repeatedly asked to re-think: Were they sure they were ready? (*Id.* at 86). And then one obstacle after another was thrown in their path. This pattern continued into 2022, when Caden was hospitalized several times with life-threatening medical issues, and his parents were "adamant" that Caden be discharged to their home, not back to Kidz Korner. But Caden was discharged to Kidz Korner each time.

And beyond the general pushback from facility staff, Care Coordinators and others, the family was told that there were certain barriers to transitioning Caden home: the size of their apartment, their need to undergo training, backordered medical equipment, and of course lack of private duty nursing staff. (DE 906 at 91). Plus, there had been no "formal" request to end Caden's institutionalization.

None of these things should have been barriers. First, regarding the size of their home, the family was simply given misinformation. Indeed, Mr. Amore and Ms. Newton conscientiously set about preparing their home to accommodate Caden once it was clear that the size of their living space was not a real obstacle. Second, the "training" barrier was somewhat disingenuous, because the facility had no formalized training process to speak of, as I'll explain in more detail later. Third, the lack of PDN and medical equipment were only "barriers" because of the State's failure to provide those services. Finally, the need for Caden's parents to submit some sort of formal request before the facility would set in motion the process of releasing Caden is an illusory obstacle, about which the parents were never informed, and which seems to have been conceptualized as an afterthought in response to litigation pressure. Later in this Order, I will further describe these barriers to Caden's (and other children's) ability to go home. These themes recurred throughout the trial, as other parents testified about encountering similar problems with "transitioning" their children from pediatric nursing facilities to home.

Caden was only just released from Kidz Korner during the pendency of this trial. Changes started to occur much more rapidly in the couple of months before Mr. Amore appeared in court to give his testimony. (DE 906 at 69-72, 73). Suddenly, Mr. Amore noticed ramped up discharge efforts and planning. He and Ms. Newton got more information, better explanations, and generally the facility was more responsive. Deliveries of durable medical equipment, which they were previously told was on backorder, began arriving at their home. Mr. Amore actually had to slow the process down some, because all of this was occurring as the family was contemplating a relocation due to a hike in rent. But all of the preparations fell into place, and shortly after Mr. Amore testified, Caden transitioned home.

Josiah, Age 15

"He deserves better.
I want him to be happy
and his happiness is with me."[19]

Martin Carrizales was deposed in his motel room in Cocoa Beach, Florida, where he was then residing with his son, Josiah. Mr. Carrizales is Josiah's sole caregiver. And Josiah's medical issues are so severe and complex as to render him entirely dependent upon his father for every basic need.

They took up residence in this motel room after the leaky roof at Mr. Carrizales's prior home finally caved in. That home was an apartment unit which Mr. Carrizales had been renting. Three days after the roof collapse, Mr. Carrizales's landlord abruptly terminated the lease. Mr. Carrizales suspects that this was the landlord's way of avoiding the cost of relocating him and Josiah while repairs to the building were underway.

At least one of Josiah's medical conditions, Marfan's syndrome, is an inherited genetic disorder; his mother died of the connective tissue condition that impacted her heart when Josiah was ten years old. Josiah also has cerebral palsy, clonus, scoliosis, and spondylosis. Josiah is non-ambulatory. He has outgrown his wheelchair, and Mr. Carrizales is having trouble acquiring a new one, so Josiah is confined to a hospital bed almost all the time. Although Josiah cannot talk, he could be heard in the background of his father's video deposition, seeming to respond for emphasis

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[19] Quoted from the deposition testimony of Martin Carrizales, father of Josiah, which can be found at DE 789-22. Excerpts from the deposition were played at trial. This quote can be found at page 40.

at certain points of Mr. Carrizales's testimony, as he was telling the story of their lives and past experiences.

Mr. Carrizales met Josiah's mother when she was pregnant with him. They married, and Mr. Carrizales took on the role of Josiah's father after Josiah was born in 2007. When Josiah was younger, he could speak some, and he called Mr. Carrizales "Dad." Josiah's mother died in 2017.

When it comes to services, Josiah receives precious little. As Mr. Carrizales testified: "the need is great, but the help is limited." (DE 789-22 at 28). Josiah qualifies for Medicaid and is under the Sunshine Health Plan, as most children in his situation are. Josiah's occupational therapy is about the only ray of hope – he gets that consistently, multiple days per week for an hour per visit. Mr. Carrizales expressed great appreciation for the provider of this service for Josiah. But he is supposed to be receiving physical therapy too. And speech therapy. He is receiving neither. Mr. Carrizales testified that therapists are "hard to find," either too far away or just not available. (*Id.* at 17).

Because Mr. Carrizales has been unable to procure necessary medical equipment to care for Josiah, he has been forced to improvise. When Josiah was small, Mr. Carrizales nailed an infant seat to a full-sized wheelchair and strolled Josiah around that way. Mr. Carrizales cannot get a bath seat for Josiah so he put together a makeshift one. Desperate to provide Josiah with some degree of stimulation or enrichment, Mr. Carrizales has created a toy for Josiah with a "hoyer lift," which is the device that lifts Josiah in and out of bed. (DE 789-22 at 24, 40). When the strap is not in use, Mr. Carrizales ties it to the ceiling and appends items to it that Josiah can look at and reach for.

Mr. Carrizales and Josiah's biggest problem is lack of access to private duty nursing. Josiah is authorized to receive 12 hours per day, plus some night hours. But there are no nurses available. Mr. Carrizales has now gone more than a year with no private duty nursing services at all. He has been providing all of Josiah's nursing care himself, at home, with no help. And even before then, nurses were unreliable, either showing up late or not showing up at all. Or they were unqualified and just physically unable to attend to Josiah's needs.

Mr. Carrizales's inability to access private duty nursing services means that he cannot work. He used to be able to take well-paying, short-term jobs fixing air conditioning units. But he cannot do that anymore because he cannot leave Josiah alone, ever. At the last steady job that Mr. Carrizales was able to hold, his boss, frustrated with Mr. Carrizales's spotty attendance record (due to no-show nurses), told him that he should consider placing Josiah in an institution. Mr. Carrizales vehemently disagreed.

Mr. Carrizales was 65 at the time of his deposition, and he explained that he is struggling with his own health issues, which he has had to largely ignore, because Josiah's needs take priority.

Mr. Carrizales has applied for Josiah to be placed in "PPEC," a pediatric prescribed extended care, akin to daycare, but for kids with medical complexity. He said that Josiah would start going that week, three times per week. But it took a year to line this up.

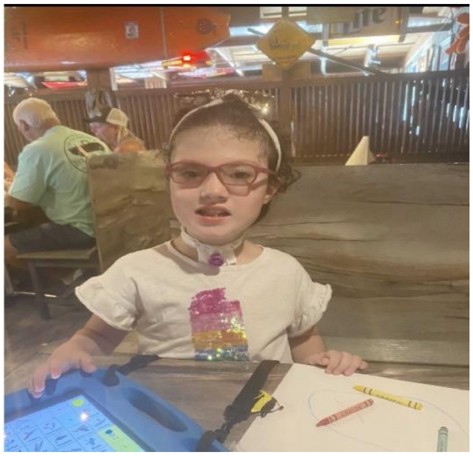
He is on a waitlist for the iBudget waiver, which his parents applied for when Josiah was 2 or 3 years old. At that time there was a two-year waitlist, then it grew to 5 years, and then 10 years. Now, Mr. Carrizales has been told that he need not apply again until Josiah is an adult.

"Care Coordination" has not been useful. As Mr. Carrizales describes it, there is a newly-assigned Coordinator "every time I turn around," and the challenge is that he tells one person what Josiah's needs are, then they leave, he repeats the same things to the next coordinator, and the net result is that Josiah's access to needed resources is delayed and prolonged. (DE 789-22 at 32). No Care Coordinator that Josiah has ever had has stayed long enough to be of any help.

Mr. Carrizales's sense is that the Care Coordinators have a desire to help but they run into insurmountable obstacles in trying to pull together resources. "[E]verything is red tape or there's always something or a reason why it can't get done or why it's…not progressing the way it's supposed to," he said. (DE 789-22 at 23). Mr. Carrizales marvels at the fact that Care Coordinators can barely accomplish anything, when they are the ones who ought to be operating from a position of power and equipped with knowledge about the intricacies of the system.

There is not much space in the motel room. Mr. Carrizales would like to be able to move Josiah around more. The frustration in Mr. Carrizales's voice was evident as he explained that Josiah is just too heavy now to lift into the car, so Mr. Carrizales can rarely get him out. He expressed disappointment that Josiah was not being exposed to the outdoors and experiencing the things he should be. He is eager to improve Josiah's quality of life. Josiah has never lived in a nursing facility. "As long as I got breath in me, that will never happen." (DE 789-22 at 39).

Olivia, Age 9



Struggling to navigate the complexities of acquiring Medicaid services for her daughter, Julie Pagano[20] said: "[I]t's a constant battle. It's an ongoing battle just to keep your head above water. Just to live everyday life is a fight. I feel like I fight for everything. . . . it's a struggle. It's scary. It's terrifying." (DE 910 at 139).

Olivia is an At-Risk child. She is now 9, and she has been medically complex since birth. She and her mother reside in a 1000 square foot apartment in Orlando. Ms. Pagano is Olivia's sole caregiver.

Olivia has a variety of severe medical issues. She was born without the ability to swallow, and she also has a particularly dangerous form of sleep apnea. Ms. Pagano was terrified when she brought Olivia home from the hospital because she was so fragile. But Ms. Pagano could not have

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[20] The testimony of Julie Pagano, Oliva's mother, is available at DE 910, beginning on page 78.

imagined doing things any other way: "She's our daughter, it's obvious, she should be in the home with us," Ms. Pagano said. (DE 910 at 136).

Olivia was in the courtroom, accompanied by her nurse, as her mother began to testify. But as Ms. Pagano started describing Olivia's fragility and their family's difficulties, she requested a break so that Olivia could be escorted out.

Ms. Pagano's testimony was remarkable in a number of respects. Partly it was encouraging, as there seemed to be a great deal of normalcy about Olivia's life despite her complex medical needs: she attends school, has friends, takes trips to the beach, has received therapy which was highly effective in enabling her to communicate through use of a device to form words and sentences. And all this despite having no meaningful Care Coordination until around 2019, and despite being in limbo on an iBudget waitlist for years.[21]

Ms. Pagano is a former real estate agent but had to give up that job due to lack of nursing coverage on Saturdays. She now works in a high-pressure commission-based job in vacation sales. She sometimes has no choice but to stay awake all night with Olivia, because no nurse is available, and Olivia requires constant supervision. She consumes caffeine and then sleeps in short intervals, setting her alarm every 15 to 20 minutes to check on Olivia, to make sure her trach is in place and that she is not in distress. While sleep deprived, Ms. Pagano has trouble functioning the next day at work. And if she loses her job, she cannot support Olivia or herself.

Ms. Pagano's testimony reflected a sense of urgency and dread as she explained her challenges caring for Olivia, on her own, without consistent nursing coverage. The precariousness of her circumstances seemed at a near-crisis level, and the extreme vulnerability of her situation was evident. Ms. Pagano related one incident that was particularly harrowing. In 2021, she contracted Covid-19, and she had no night nursing coverage for Olivia. Olivia's condition is such that she stops breathing in her sleep, therefore it is especially dangerous for her to be unmonitored throughout the night. Ms. Pagano tried her best to manage, finding herself very sick and suddenly alone with Olivia. She was horrified to wake up the next morning in a urine-soaked mattress next to her daughter, who thankfully survived the night, but both of them were shaken.

Olivia's night nurse, Rancy, has been trying to relocate since December of last year, but he has stayed on with the family out of sympathy, until a replacement can be found. Ms. Pagano was asked what would happen to Oliva if they lost night nursing coverage if Ms. Pagano could not work, or if she lost her job. Her answer: "I don't even want to think about it[.]" (DE 910 at 120).

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[21] Regarding Ms. Pagano's Care Coordination issues, she described an incident regarding her difficulty in obtaining an item of durable medical equipment for Olivia. Olivia's CPT vest is critically necessary to avoid Olivia contracting pneumonia and requiring hospitalizations. It vibrates and breaks up fluids in her chest. But no one told Ms. Pagano that it was potentially available. She saw the vest being used somewhere, and she proactively inquired about it. Once she identified the vest as being useful and relevant to Olivia's care, she requested it on her own, but she was met with obstruction and delay from doctors.

Carena, Age 5

"I need to represent my daughter. She can't speak for herself."[22]

Michael Rodriguez, a corrections sergeant with the Florida Department of Corrections, with a newly born daughter only four days old, explained why he drove three hours to court in order to testify about his firstborn, Carena.

Carena, who is now five years old, is subject to seizures, has difficulty maintaining her body temperature, and requires a gastrostomy feeding tube ("G-tube") and pump because she cannot swallow on her own. She also requires oxygen on an as needed basis. She has resided at Sable Palms, a nursing facility in Largo, Florida, since she left the hospital after birth. Sgt. Rodriguez wants her to live with her family, at home.

He describes his daughter as "usually happy. Very rarely is she sad or upset. Every time I see her, she loves to play jokes on me and her mom, mostly me." (DE 909 at 7). He is only able to see her once a week, on his day off, for about an hour, with a two hour drive. But he wants to be able to see her "[e]very day when I wake up in the morning." (*Id.*)

Carena left the hospital when she was three months old. The Care Coordinator at the hospital and the Department of Children and Families (DCF) advised Carena's parents that "[t]he only option was for her to go to a nursing facility that – so that they can take care of her medical needs." (DE 909 at 13). There was no mention of any transition assistance benefits through Children's Medical Services (CMS), group homes, or medical foster care. When Carena went to the nursing facility, Sgt. Rodriguez thought it was only to be for a short time "maybe a month. We were told that it wasn't a long process to bring her home." (*Id.* at 15). When she was first admitted we "expressed to them that we wanted to bring her home." (*Id.*). But no services were offered to make that happen.

Sgt. Rodriguez worked extensive overtime to earn enough money to purchase a home with enough space to accommodate Carena – "[e]very 80 hours, I did an extra 40." (DE 909 at 16). He and his wife were trained on the equipment needed "at least twice." (*Id.* at 37.) "[W]e were told that there was a nursing shortage, and it might delay or extend the amount of time needed to bring her home." (*Id.* at 18.)

When asked why his wife has continued to sign the Freedom of Choice form indicating that the family wanted Carena to continue living at Sabal Palms, Sgt. Rodriguez responded: "From my understanding, we need to continue saying 'yes' so that she can continue receiving the medical care there at Sable Palms." (DE 909 at 23). He was then asked what it would take for him to indicate, on that form, that he wanted Carena home and not at the facility. He answered:

> Just some assistance on getting the process started and continued. From my understanding we need a medical bed at home. We need a private duty nurse. That's just stuff we don't know how to do on our own. We know how to do all the trainings that we've done there. We

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[22] Quoted from the trial testimony of Michael Rodriguez, Carena's father, available at DE 909, beginning on page 3. This quote can be found at page 40.

> know how to change her G-tube, clean it. We know how to operate her heating pad, operate the pump, operate the oxygen; we just don't know how to get nursing and the assistance to get her home. (DE 909 at 24).

Jeffrey, Age 15

Eve Harris has three children and eight grandchildren. Since 2015, she has been the legal guardian of Jeffrey, one of her grandsons, a 15-year-old child with medical complexity who receives Medicaid benefits.[23]

As a direct result of lack of adequate private duty nursing coverage, Jeffrey was institutionalized for the roughly 16 months immediately preceding the trial in this case. He just transitioned home in April of this year.

Ms. Harris was in the Navy. She has several healthcare licenses and certifications. She once aspired to be Jefferey's personal nurse, and she was taking classes in nursing school, but she had to drop out because Jeffrey's needs were too great, and she lacked services.

Jeffrey is medically fragile, but Ms. Harris described his personality and his capabilities. Jeffrey is blind and has other significant physical limitations. But he responds to verbal cues, and he communicates with others in his own way. In the home environment, he interacts with people in the house, although his responses are typically delayed. He enjoys listening to cartoons. Jeffrey's cousin Antonio assists with Jeffrey's care. He takes Jeffrey out of the house to ensure that he gets fresh air. Jeffrey has trouble regulating his body temperature, so it is difficult for him to go out very often, but he sometimes goes shopping and on other trips with family members.

Ms. Harris also described Jeffrey's specific diagnoses, his medical care, and his daily needs. Jeffrey suffered "a brain aneurysm that left him with cerebral palsy, epilepsy, [and] spastic quadriplegia." (DE 907 at 6). He is G-tube dependent, uses a feeding pump, trach, ventilator, cough

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[23] The testimony of Ms. Harris, Jeffrey's grandmother is available at DE 907, beginning on page 4.

assist machine, nebulizer, chest therapy vest, oxygen concentrator, and wheelchair. Jeffrey requires constant care.

Indeed at night, the risks increase somewhat, because he utilizes a BiPAP machine that covers his nose and mouth. This must be monitored closely to ensure that secretions do not build up underneath, which require suctioning, otherwise he could aspirate these emitted fluids, which would be dangerous, even fatal. It is an unpredictable situation. Ms. Harris explained that Jeffrey's nurses had to stay in the room with him constantly throughout the night to watch for this aspiration risk under his BiPAP mask. But Ms. Harris knew Jeffrey's breathing patterns so well that she could sense changes in a more intuitive way.

Many parents and caregivers, like Ms. Harris, described this phenomenon: becoming acutely attuned to their children, hyper-aware, and able to detect subtle changes in breathing patterns or other signals that outsiders miss. There are practical benefits to caring for a medically complex child in a home environment.

Ms. Harris described difficulties she has experienced in obtaining various types of services for Jeffrey, but particularly the problems she articulated relating to access to private duty nursing were extraordinary. The issues were so severe that Ms. Harris sold her home, relocated, and made the difficult decision to place Jeffrey in a nursing home.

Jeffrey was authorized for 12 hours per day, but he did not receive it. And the coverage was critically necessary so that Ms. Harris could work and attend school. Ms. Harris is certified as a home nursing assistant, and before Jeffrey's institutionalization, she worked as a home health aide and companion. She also previously had a job involving personnel paperwork for the military, but she lost that position in 2018 due to Jefferey's needs and her consequent inability to keep a consistent work schedule.

On occasions in which she suddenly found herself to be without nursing coverage, which happened frequently, Ms. Harris would pack Jeffrey up and take him with her to wherever she was working as a home health aide. But it was difficult to care for him under those circumstances, as she had to attend to her job responsibilities. On such days, she would always ensure that Jeffrey was fed and had his medications, but she could not always get his diapers changed on time. And the nursing no-show issue became particularly complicated on days when it rained, because Jeffrey could not get wet. On those days, Ms. Harris could not report for work on time, or she would have to miss work altogether.

Ms. Harris addressed the PDN lapses and other issues with her Care Coordinators in or around April and May of 2021. She explained her circumstances with work, her inability to drag Jeffrey around with her to her job sites. She also called the nursing agency herself several times. She was led to believe coverage was coming, but it never did, or at least not reliably. Because Ms. Harris could not work consistently, she ultimately lost income, which resulted in her losing her home. The Care Coordinators were aware that the family was in a dire situation.

Aside from PDN, Ms. Harris described other problems getting services for Jeffrey, who is covered under Sunshine Health, a Medicaid managed care plan. Various coordinators were assigned to Jeffrey's case at various times and in various locations. There was no consistency. And while sometimes Ms. Harris was satisfied with their services, at other times Ms. Harris had to take on the Care Coordination role herself, ordering her own supplies, scheduling Jeffrey's appointments, and the like. No one helped her. She estimated that between the years of 2010 and 2018, she had very little help from Care Coordinators at all. A Coordinator was assigned, but the person did not check in on the family. Ms. Harris did not know enough about the system to know what she was entitled to, whether to complain, how to complain, or whom to complain to.

Jeffrey was authorized to receive PPEC placement but he never obtained that service.

When she lost her house and it came time for Ms. Harris to relocate, she was very hopeful that moving to a more populated area would facilitate her ability to receive services for Jeffrey. Perhaps in a larger city, there would be more than one provider of medical equipment, more than one PPEC option, better Care Coordination, and additional resources. But that was not the case. She eventually felt she had no choice but to place Jeffrey in a nursing home. She did not want to, but she could not care for him at home without resources.

The first place she tried to take Jeffrey was Kidz Korner. This was in September of 2021. However, Jeffrey had a severe panic attack almost immediately upon arrival at the facility. His aversive response to being separated from Ms. Harris was so extreme that he had to be immediately hospitalized at Joe DiMaggio Medical Center, where he stayed for an entire month before he was stable enough to be released.

From Joe DiMaggio, Jeffrey was placed at the Sable Palms nursing facility, where he lived for a year before moving to Broward Children's Center ("BBC") in November of 2022. His stint at BCC was interrupted by a six-week hospitalization beginning in February of 2023. And from that hospitalization, he finally moved back home. That was in April of 2023.

Ms. Harris talked about what life was like for her and for Jeffrey while he was residing in nursing facilities. She was highly concerned because his health declined, and he kept sustaining injuries. He was hospitalized several times. Moreover, he went into the nursing facility reliant upon only five medications, and he came out reliant upon 18. His basic health needs changed for the worse: he became ventilator dependent, whereas before he was not.

And when Ms. Harris was able to visit Jeffrey – which was not frequently enough due to the financial constraints associated with traveling – she found herself preoccupied with the physical demands of caring for his medical needs, not spending quality time with him. Moreover, Ms. Harris was concerned about his inability to communicate with anyone at the facility. She was sad when she had to leave him.

Beginning around August of 2022, Ms. Harris told her Care Coordinator that she wanted to bring Jeffrey home. She expressed the concerns she was having about his care while institutionalized.

Although she continued to sign "Freedom of Choice" forms throughout Jeffrey's institutionalization, she felt that she was signing out of necessity. "[T]hey told me I needed to sign." (DE 907 at 32).

There were hurdles to transitioning home. Facility staff at Sable Palms told her she needed to be trained, and so did her son. The training process was disorganized. There was confusion and/or a lack of communication about precisely what the training entailed and what proficiencies they had to demonstrate. Ms. Harris was later told by the staff at BCC, where Jeffrey eventually moved, that she would have to perform the same training over again. She did. But afterwards, a social worker at BCC advised Ms. Harris that she still could not bring Jeffrey home because there was no commitment that she would receive adequate private duty nursing hours.

In February of this year, distressed and at her wits' end, Ms. Harris initiated a conversation with the CEO of BCC. She complained about a number of things: Jeffrey's substandard care was resulting in injuries, which she felt the staff was covering up. She suspected that the staff made her wait at visits as a delay tactic so that "they could clean him up" first. (DE 907 at 39). She complained about having to make appointments before she could visit with Jeffrey – for instance, after driving 45 minutes to see him on Christmas Eve, she was turned away for failing to make an appointment.

Following Ms. Harris's conversation with the CEO, Jeffrey was hospitalized. He was suffering from symptoms of cellulitis and septic shock. He spent six weeks in treatment.

After his most recent hospitalization, Jeffrey was released to the care of his grandmother. Now that Jeffrey is at home, Ms. Harris says that he is happier, responsive, healing, and not so "sickly." (DE 907 at 40). He engages with family and friends, including on videocalls.

Jeffrey is authorized for 12 hours per day of private duty nursing, and a PPEC placement. On the date Ms. Harris testified, Jeffrey had not received all of the nursing hours that week. A nurse had called out on Sunday and no replacement came, so that night Ms. Harris stayed up and took care of him.

Ms. Harris desperately wants Jeffrey to remain at home. She is so adamant that Jeffrey not ever be subjected to nursing home placement again that she said she intends to keep him at home, with or without adequate PDN.

VI. OVERVIEW OF FLORIDA'S MEDICAID PROGRAM

Understanding how Florida implements Medicaid and the various services it provides is critical for determining whether, and if so to what extent, Florida is failing children with medical complexity. Perhaps most importantly, it illuminates the opportunities that will allow children with medical complexity to finally exit nursing facilities and reduce the risk that they or others will be forced to re(enter) such facilities.

Dr. Sara "Sally" Bachman testified about Florida's Medicaid plan and administration.[24] Dr. Bachman has extensive expertise in evaluating Medicaid programs throughout the country and is one of the nation's leading experts in Medicaid program policy, structure, and financing. She has focused a large part of her research on evaluating the provision of Medicaid programs for children with medical complexity. She clearly explained how Florida runs its Medicaid program through its state agency—Florida's Agency for Health Care Administration ("AHCA")—and how AHCA interacts with other state agencies to provide services for Florida's most vulnerable population, children with medical complexity. Most of the following explanation comes from her impressive testimony as well as agreed upon facts distilled in the Parties' Pretrial Stipulation (DE 840, Pretrial

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[24] Dr. Bachman's testimony is available at DE 909, beginning on page 41.

stip., VI).[25] Florida's witnesses from AHCA, as well as other agencies, confirmed her explanation.

Medicaid is a program that is jointly funded by the state and federal government that provides medically necessary services to individuals who meet income eligibility requirements. (DE 909 at 45). Most children with complex medical needs are covered by Medicaid. (*Id.*). Florida, as a participant in the Medicaid program, must provide a State Plan, which details the nature and scope of its program and must be approved by the federal government's Centers for Medicare & Medicaid Services. *See* 42 U.S.C. § 1396a; 42 C.F.R. § 430.10. (DE 909 at 62; DE 840, Pretrial stip., VI, ¶¶ 2, 5). The State Plan outlines what services Florida must provide, when medically necessary, to Medicaid enrollees, including children (under the age of 21). *See* 42 U.S.C. §§ 1396(a)(43), 1396(a), (r)(5). DE 909 at 64). Like all states that participate in Medicaid, Florida defines its own "medical necessity" criteria. *See* 42 U.S.C. § 1396a(a)(17). (DE 909 at 65). If Florida determines that a service is medically necessary, Florida must provide the service to the Medicaid recipient. (DE 840, Pretrial stip., VI, ¶¶ 7, 34, 35, 45).

A. Administration of Services: Managed Care Plans and Fee-For-Service

AHCA is the sole state agency responsible for administering Florida's Medicaid program. In doing so, it provides services to recipients through either a managed care plan or a fee-for-services program. Florida delivers Medicaid services to most of its Medicaid recipients through its Statewide Medicaid Managed Care (SMMC) programs, which AHCA administers. *See* Fla. Stat. § 409.965. (DE 840, Pretrial stip., Section VI, ¶ 9). Essentially, AHCA contracts with private companies—managed care organizations—to provide medically necessary services to Medicaid recipients enrolled in managed care plans. (DE 909 at 78). The State pays each managed-care plan a monthly amount per enrollee based on per-member-per-month capitated rates, and managed-care plans pay enrollee's providers according to rates they negotiate with those providers. (DE 840, Pretrial stip., Section VI, ¶ 11). The AHCA contracts set forth certain provider network requirements, including the minimum number of provider types. Relevant to this case, each contract requires that the plans have two home health agencies per county, whether rural or urban. (DE 894 at 178). Florida typically pays managed care plans a flat rate per member per month under a contract. (DE 909 at 43). Then, the managed care plan is required to provide all medically necessary services that the Medicaid recipient requires, as set forth in the contract. (DE 909 at 43; DE 897 at 25). To do so, the managed care plan negotiates contracts with service providers to ensure that its members have access to providers in all categories of care, *i.e.*, ensuring network service adequacy. (DE 897 at 26). Nevertheless, AHCA has full responsibility for the implementation of managed care plans. (DE 909 at 78-79).

By contrast, a fee-for-services program is where AHCA pays a flat rate to providers for every service provided. (DE 909 at 86-87). AHCA sets the provider reimbursement rates for the fee-for-services program, whereas a managed care plan sets the provider reimbursement rates for its plan. (DE 909 at 83, 88). However, AHCA has oversight over the rates paid by managed care plans. (*Id.* at 83.) In addition, although managed care plans typically pay providers at set rates, they sometimes enter what are known as single case agreements, whereby they agree to provide higher reimbursement rates to incentivize a provider to provide care for an individual. (*Id.* at 118.)

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[25] This Order incorporates by reference all the agreed upon facts set forth in the pre-trial stipulation submitted by the Parties on April 12, 2023. (DE 840, Pretrial stip. VI "Uncontested Facts").

Most children with medical complexity in Florida are covered by a managed care plan, although a minority of children receive care through a fee-for-services program. (DE 909 at 87). One of the programs under the SMMC program is the Children's Medical Services Health Plan (CMS Plan), which is administered by the Department of Health; the Department of Health in turn contracts with Sunshine State Health Plan, Inc. ("Sunshine Health") to assist with the administration of the CMS Plan. (DE 909 at 79-80; DE 840, Pretrial stip., VI, ¶ 18). The CMS Plan is geared toward children with special health care needs, which includes children with medical complexity. (DE 909 at 79-80). However, children with medical complexity are not required to enroll in this plan. (DE 909 at 80-81).

B. Involvement of Other State Agencies and Third Parties

AHCA works with other state agencies, three of which are particularly relevant here: the Department of Health, the Agency for Persons with Disabilities, and the Department of Children and Families. (DE 909 at 78). As discussed above, the CMS Plan falls under the purview of the Department of Health. The Agency for Persons with Disabilities runs the Developmental Disabilities Individual Budgeting (iBudget) waiver program, which can provide supportive services for children with medical complexity to live at home or in community settings. The Department of Children and Families runs the Medical Foster Care program.[26]

Despite contracting with private managed care companies and working with other state agencies, AHCA is ultimately responsible for ensuring the provision of Medicaid services. *See, e.g.*, Fla. Stat. §§ 409.963 (designating AHCA as the single state agency responsible for management, operation, and payment for services delivered through the SMMC program); 409.967(2)(c) (requiring AHCA to, *inter alia*, "establish specific standards for the number, type,

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[26] The Florida Legislature has expressly recognized the necessity for AHCA and other state agencies to work together to ensure health care for special needs citizens, especially with respect to Medicaid. In the Health Care and Insurance Reform Act of 1993, the Florida Legislature created Fla. Stat. § 408.301, declaring legislative findings and intent relating to health care. That section, as amended, states:

> The Legislature has found that access to quality, affordable healthcare for Floridians is an important goal of the state. The Legislature recognizes that there are Floridians with special healthcare and special needs which require particular attention . . . The Legislature further recognizes that the Medicaid program is an intricate part of the service delivery system for special needs citizens. However, the Agency for Health Care Administration is not a service provider and does not develop or direct programs for the special needs citizens. Therefore, it is the intent of the Legislature that the Agency for Health Care Administration work closely with the Department of Health, and the Department of Elderly Affairs in developing plans for assuring access to all Floridians in order to assure that the needs of special needs citizens are met.

Fla. Stat. § 408.301.

and regional distribution of providers" delivering services to SMMC recipients); 409.973 (describing Medicaid services to be made available through managed care plans); 409.98 (describing Medicaid services to be made available through long-term care plans). In its State Plan, AHCA also agrees to monitor the performance of managed care plans to ensure access to care, compliance with contracts, and the provision of an adequate provider network. (DE 840, Pretrial stip., VI, ¶¶ 13, 15). To that end, AHCA's contracts with managed care plans provide several mechanisms that AHCA can employ if the managed care plan falls short, such as a corrective action plan, liquidated damages, and sanctions. (DE 909 at 85-86). In addition, AHCA controls licensure requirements for at-home providers and establishes fee-for-services reimbursement rates for such providers. *See, e.g.*, Fla. Stat. §§400.062 (establishing licensure requirements for nursing facilities through AHCA); 400.464 (establishing licensure requirements for home health agencies through AHCA); 409.908 (describing available reimbursement methodologies for Medicaid providers); Fla. Admin. Code R. 59G-4.002(3)(aa) (establishing fee schedule for private duty nursing services effective Jan. 1, 2022).

C. Institutionalization

Children with medical complexity are served by Florida's Medicaid program in both institutional and home or community settings. (DE 840, Pretrial stip., VI, ¶ 23). Florida's Medicaid program covers approximately 140 children with medical complexity in nursing facilities. (*Id.* at ¶ 26.) Those children live at one of three nursing facilities: (1) Children's Center at Sabal Palms Health and Rehabilitation (Largo, Florida), (2) Children's Comprehensive Care Center, known as Broward Children's Center (Pompano Beach, Florida), or (3) Plantation Nursing and Rehabilitation Center, known as Kidz Korner (Plantation, Florida). (*Id.* at ¶¶ 23, 25, 28.) Under a fee-for-services program, Medicaid reimburses these facilities at a rate of up to $679.01 per day per child, whereas a managed care plan reimburses at the same or higher daily rates. (DE 785-32 at 48-49).

To admit a child to a nursing facility, Florida requires that a Children's Multidisciplinary Assessment Team (CMAT) meet, decide whether a child meets the level of care criteria for admission to a nursing facility, and if so, make a recommendation to admit the child. Fla. Admin. Code R. 59A-4.1295(3)(b). The CMAT is made up of representatives from various state agencies, including AHCA, the Department of Health, the Agency for Persons with Disabilities, the Department of Children and Families, and any managed care plan. *Id.* Florida's internal procedures require that CMATs use a family-centered approach to facilitate appropriate service delivery. (DE 977-1 at 118, USA Ex. 3442 at FL12199335). Importantly, they must provide information about alternatives to a nursing facility. (*Id.*).

The State regulates the care and discharge planning for children residing in nursing facilities. *See* Fla. Admin. Code R. 59A-4.1295 (2016); DE 840, Pretrial stip., VI, ¶¶ 26, 29, 32.

VII. FLORIDA'S FAILINGS: HOW THE STATE IS DENYING ACCESS TO CRITICAL SERVICES

The Medicaid Act's Early and Periodic Screening, Diagnostic and Treatment ("EPSDT") provisions require states who participate in the Medicaid Program, e.g., Florida, to cover all services that are: a) provided to recipients under 21 years of age, b) the Medicaid Act permits or requires the state to cover under a Medicaid State Plan, and c) are medically necessary to correct or ameliorate defects, physical and mental illnesses, and conditions. (DE 840, Pretrial stip., VI, ¶ 6).

Said more simply, Florida's Medicaid program must provide EPSDT, which requires the provision of all medically necessary services to children with medical complexity, including private duty nursing ("PDN") and Care Coordination. In addition, Florida's Medicaid program offers two other services that can support children with medical complexity in a home or community setting: the iBudget waiver and Medical Foster Care. Dr. Bachman discussed all of these services during her testimony. The State's Medicaid expert, Gary Jessee, also discussed these services.[27]

Various witnesses for both the United States and the State testified as to how Florida is actually providing these services to children with medical complexity. As reflected by the testimony of experts and the families of children with medical complexity, Florida is failing to do so. In addition, experts testified that Florida could better monitor its managed care plans and utilize existing mechanisms provided in its managed care contracts to hold the plans accountable when they fail to provide Medicaid services to children with medical complexity.

A. Private Duty Nursing

PDN is provided under EPSDT. (DE 897 at 135-36). PDN is a critically important service for children with medical complexity because they require highly skilled nursing care. (DE 909 at 94). PDN allows a child to receive one-on-one nursing care from a skilled nurse; PDN can be provided in institutions or at home. (*Id.* at 82-83). Managed care plans contract with home health agencies to provide PDN to children at home. (*Id.* at 83). To obtain PDN, a provider must indicate that a child needs PDN; then, the managed care plan reviews and authorizes the child for a certain number of hours of PDN. (*Id.* at 95). Children with medical complexity may receive authorization for around-the-clock PDN (*i.e.*, 24 hours a day/7 days per week). (*Id.* at 96).

The testimony showed that the main impediment to children leaving nursing facilities is the lack of PDN. In addition, the lack of PDN is a significant factor that places children with medical complexity who are living at home at risk of entering a nursing facility.

1. *The Data Supports a Finding that Families are Being Denied Access to Adequate PDN.*

Dr. Bachman evaluated how well Florida provided PDN to children with medical complexity. (DE 909 at 96-97). To do so, she requested data from Florida to conduct a program evaluation of the provision of PDN for children with medical complexity in Florida. (*Id.* at 97). Florida provided data in the form of ad hoc reports for a one-year period, fiscal year 2021 (October 1, 2020-September 30, 2021). (DE 909 at 97-98; DE 908 at 132; DE 912 at 33). The ad hoc reports, which were mandated by the legislature only for fiscal year 2021, were prepared by the managed care plans as simple Excel spreadsheets. (DE 909 at 98; DE 908 at 29). The ad hoc reports contained information about the enrollee, the number of PDN hours authorized, and the number of PDN hours received by the enrollee. (DE 909 at 98). In addition, there were comment boxes. (DE 909 at 98). This data did not include all children with medical complexity receiving PDN services in Florida, but rather came from seven managed care plans in which children with medical

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[27] Mr. Jessee's testimony is available at DEs 897 and 912.

complexity were receiving PDN services. (DE 909 at 98-99). The ad hoc reports were prepared by the managed care plans in an effort to receive funds withheld by the State for lack of PDN.[28] As a result, I find that the managed care plans had a financial incentive to provide accurate, if not inflated, data showing that they provided PDN hours that were authorized. (DE 912 at 34).

Dr. Bachman—with the assistance of Emily Sisson, who also testified—compared the number of PDN hours children received versus what they were authorized to received. (DE 909 at 99). Ms. Sisson, who is a statistical data analyst, detailed her methodology for preparing the data from the ad hoc reports and conducting the analysis.[29] The results showed that almost 94% of the children with medical complexity received fewer PDN hours than they were authorized to receive. (DE 909 at 100). Of the 1,956 children included in the data, almost 1,800 received fewer PDN hours than authorized by the managed care plans. (DE 909 at 100; DE 908 at 171). Stated another way, only 6.5% (or 128 children) received all of their authorized PDN hours. (DE 909 at 100; DE 908 at 171). Ms. Sisson explained that on average, children received 70-80% of their authorized hours. (Sisson 170:16-18). 1,800 children are not receiving medically necessary services, which Dr. Bachman opined places them at risk. (Bachman DE 909 at 100-101).

Dr. Bachman found that 58% of the children received less than 80% of their authorized PDN hours. (DE 909 at 101). About 25% of the 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." (*Id.*). Ms. Sisson confirmed that only 6% of children received 24 hours/day of PDN whereas 22% of children were authorized for 24 hours/day of PDN. (DE 908 at 138). Looking at the data by county, Ms. Sisson testified that in the majority of counties, only 0-40% of the children received 90% or more of their authorized PDN hours. (*Id.* at 142). However, in two counties, 81-100% of the children received 90% or more of their authorized PDN hours. Dr. Bachman opined that these results suggest that there is an access-to-care problem. (DE 909 at 100).

Dr. Bachman also examined, using Ms. Sisson's analysis, whether there were any geographic patterns in the data, such as differences in the number of PDN hours received based on whether children resided in rural or urban counties or in counties with small or large populations. (DE 909 at 105-108). However, she found no patterns based on where children resided, either by geographic variation (rural v. urban) or population size. (*Id.* at 106, 108). She opined that based on her review of data by counties, a national nursing shortage is not primarily responsible for the gaps in providing PDN. (*Id.* at 109). Mr. Jessee agreed that the nursing shortage was not the primary factor for the PDN utilization rate in Florida. (DE 897 at 42).

In addition to the ad hoc reports for fiscal year 2021, Dr. Bachman also received data from Sunshine Health for June 2022 covering about 2,000 children. (DE 909 at 110). The purpose of examining this data was to see whether the provision of PDN hours improved after the pandemic had eased. (DE 908 at 161-62). Ms. Sisson conducted a similar analysis of the data from June 2022 and found similar results. In a limited subset of counties, 80-100% of children received 80% of their authorized PDN hours or more. (DE 909 at 111-12). In two counties, some children received

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[28] During fiscal year 2021, Florida withheld 1% of the capitation rate that it pays to managed care plans for PDN. To obtain some of the withheld funds, managed care plans were required to submit the ad hoc reports. (Jessee (2nd)).

[29] Ms. Sisson's testimony is available at DE 908, beginning on page 122.

0–20% of their authorized PDN hours. (*Id.* at 112). Statewide, more than 50% of authorized PDN hours were not paid. (*Id.*). Dr. Bachman did not review any other PDN data because such data were not collected; the ad hoc reports were only gathered for a one-year period. (*Id.* at 99). Mr. Jessee, who did not criticize Ms. Sisson's methodology, ran the same analysis on the data from the ad hoc reports and obtained the same results. (DE 912 at 36).

Dr. Bachman explained that there are a variety of reasons why a child might not be receiving all of their PDN hours, but that the data provided by Florida did not allow her to conduct any analysis to uncover those reasons.[30] (DE 909 at 112). She explained that Florida could collect more data to try to understand this issue better. (*Id.* at 112-13). Mr. Jessee agreed that the ad hoc reports were insufficient to understand why children with medical complexity were not receiving their authorized PDN hours. "Based on the information provided on the report, you know, clearly, it was impossible to understand what the potential implications would have been as to why an authorization and utilized [PDN] hours were not consistent." (DE 897 at 30).

In addition to data analysis, Dr. Bachman also reviewed deposition testimony where it was indicated that the State was aware of gaps in PDN services, including reference to budgetary requests for additional funding for such services. (DE 909 at 119). Her review also showed that Sunshine Health has begun an initiative of contracting with two home health agencies and that the State is involved with that. (*Id.* at 119-20). Other than that initiative, she did not see any other indications that the State was actively trying to address the lack of PDN services. (*Id.* at 120).

Based on her evaluation of the documents, data analysis, and deposition testimony, Dr. Bachman concluded that "Florida does not sufficiently serve children with medical complexity in the community in terms of the provision of private duty nursing services." (DE 909 at 120). Based upon her testimony and the State's expert, Mr. Jessee, that of the parents, and all of the witnesses including those called by the State, I find that to be undoubtedly true.

2. The Problem is Widespread

Throughout the trial, the State took the position that the federal government has not shown that there exists a sufficiently widespread problem to warrant the systemic relief it requests. I disagree. The evidence showed that the failings were not limited to one child or one circumstance. They were not limited to the pandemic. The failings have happened before, and they are continuing.

The numbers reflect the widespread nature of the problem. Most children with medical complexity are not receiving their authorized PDN hours. Of the children whose families testified at this trial, four of them were institutionalized for some period of time as a direct consequence of

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[30] I note that although Dr. Bachman did not have sufficient data to make any definitive assessment of the precise reasons for low PDN delivery, other evidence adduced at the trial sheds some light on this issue. For one, nurses are not paid enough. Second, the managed care plans are not dealing effectively with home health agencies. Moreover, there are lapses in oversight and data collection necessary to ascertain causes of the failure. And Florida is also not doing enough to incentivize compliance with its contracts, as will be discussed in greater detail later in this Order, when I explain the remedy.

lack of PDN. Jeffrey was institutionalized for 16 months because his family had inadequate nursing coverage. Jamiah lived at home for 13 years before having to move into a nursing facility because his parents could not get sufficient PDN coverage (he was authorized for 24 hours a day and his parents estimate he received half that). Dalton's mother stated their nursing coverage, "was consistently inconsistent" and Dalton ended up institutionalized because of it. (DE 907 at 92). Christian's mother, Crystal Nelson said "[o]ur backs were against the wall" with only 80 percent of their nursing hours covered, and they felt they had no choice but to send him to an institution. (DE 789-26 at 23-24, 32). Two other families who testified – Caden's parents and Carena's parents – said that they experienced delays in getting their children discharged due to inability to secure PDN coverage. These families were told there was a nursing shortage.

The State's own witnesses reflect the severity of the problem with PDN deficits. Brenda Legge has been the director of pediatric nursing for fifteen years at the Sable Palms facility. She confirmed that the lack of around-the-clock nursing was the biggest obstacle to discharging children with a medical complexity home, that parents acknowledged this, and that some parents often feared taking their kids home because they wanted them to be equally safe as they were at the facility. (DE 912 at 279). Of the children residing at Sable Palms at the time of Ms. Legge's testimony, three of them were there *as a direct result* of their families' lack of access to reliable PDN. Specifically, she spoke of K.B., who is 22 years old, and has been residing at Sable Palms since she was eight. Ms. Legge said that K.B.'s mother could not get consistent nursing coverage and was on the verge of losing her job, so she brought K.B. to Sable Palms. Ms. Legge said that institutionalizing K.B. was a "very difficult decision for [her] mom." (DE 912 at 253). Ms. Legge also spoke of E.M., now a teenager, who has been at Sable Palms since the age of 11 and had lived with her family previously. But they could no longer care for her because of unfulfilled nursing needs. A third child, whose initials were not mentioned (referred to as C0048) was residing at home with her family for a short time after a car accident which rendered her technology dependent. However, the family decided to institutionalize her after they went four days and four nights with no nurse. Her mother was exhausted and could no longer keep her at home.

Laura Weaver, a case manager for Sunshine Health, also called as a witness for the State, has a caseload of 36 children, about half of whom are authorized for 24 hour care. Some of those children have had gaps in care lasting several months. She testified that she has had families with gaps in coverage of over 90 hours a week. She says the families express their frustration to her, but there is nothing she can do but present them with their options – stay with the same agency and see if the agency can recruit staffing – or change agencies. (DE 899 at 157-158).

The consequences of this failure can be deadly. Kelsey Koehler, the RN Care Coordinator for the Bower Lyman Center for Medically Complex Children, testified about a patient who had PDN ordered for 24-hour care. Because of staffing gaps, the mother was alone with her baby who had a critical airway and a tracheotomy. "She placed him in his crib to go do laundry. And when she came back, he had pulled his trach out, and he ended up dying from that incident." (DE 908 at 112-13).

In light of the testimony, I find that the lack of PDN is a huge barrier to children with medical complexity living in a home or community setting.

B. Care Coordination

Families taking care of medically complex children are overwhelmed. The stress and emotional exertion involved in worrying about and caring for the physical needs of a medically fragile child are immense. There are also herculean efforts that go into identifying and accessing a dizzying array of disjointed services, such as PPECs, therapies, waiver services, etc.

Care Coordination is a service provided by a trained person, usually a nurse or social worker, to ensure that a child's care plan is delivered in the manner intended. (DE 909 at 93). Given that children with medical complexity require a wide range of medical and supportive services, Care Coordination is essential. (*Id.*). Florida's managed care plans provide Care Coordination for the majority of children with medical complexity. (*Id.*). However, eQHealth/Kepro provides Care Coordination for children enrolled in the fee-for-service program who reside in a nursing facility or receive PDN. (DE 896 at 194). The State requires Medicaid managed-care plans to report monthly on enrollees under the age of 21 who receive nursing-facility services or PDN; this report is called the Enhanced Care Coordination (ECC) report. (DE 840, Pretrial stip., Section VI, ¶ 95).

The problems highlighted at trial with respect to Care Coordination were: (1) (especially in the provision of PDN), Care Coordinators are unable to effectively deliver the services their companies have contracted to provide in terms of helping families to identify relevant and necessary services and then helping families get those services; (2) families were not being provided with information about alternatives to institutionalization and about what services are available to help them should they choose home or another community-based placement; (3) even those families who are determined to bring their kids home faced substantial barriers in the form of disorganized training and a general lack of understanding about what is required in order to get their children discharged (*i.e.*, a "formal" request?); and (4) there is a failure to provide necessary tools and reporting mechanisms to ensure delivery of services.

But while some parents who testified reported disturbing accounts of their experiences with specific coordinators, I generally found those Care Coordinators who testified to be dedicated, competent, and genuinely concerned about the children and families they serve. Particularly with the provision of PDN, they share the same frustrations as the parents and are powerless to address them in any meaningful fashion.

1. Care Coordinators Are Unable to Facilitate Families' Access to PDN.

Kelsey Koehler, the RN Care Coordinator, previously worked for a pediatric home health company and now works directly with Care Coordinators for the managed health plans. She reports that in her experience, of the 90% of cases that have staffing issues, only 20 to 30% of her cases could be fully staffed; the remainder would only receive approximately 70% of their hours. Additionally, "on a regular basis" children's families would need medical equipment and could not get it because of problems with their insurance coverage. (DE 908 at 107).

She sees pay as a significant problem. She testified that when she worked in home health and had an open shift for a patient for many weeks in a row, they would become concerned they would get an AHCA complaint. "So the agency would start to offer more money for that shift in order to get it covered. And as soon as we started offering more money, the shifts would start to be covered." (*Id.* at 113).

Pamela Buchanan, a care manager with Humana, was called by the State. She is experienced, appears very competent, cares about her patients and enjoys her work. She agrees that it is difficult to get PDN staffing and estimated about 50% of parents receive full nursing staffing. She acknowledges that parents have told her they have had a hard time keeping their jobs because they haven't been adequately staffed. Single case agreements are a tool she uses to address inadequate staffing. More money can be offered or an out-of-network provider can be utilized. She testified that it is possible to have two agencies work on the same case, but it seldom happens because "[a]gencies do not want to work together." (DE 899 at 112).

In her experience, low pay for private duty nursing impacts the ability to achieve full staffing: "most people are going to go where the money is unless they are extremely passionate about what they do." (DE 899 at 116).

She acknowledges that switching private duty nursing agencies is a big deal for parents. "There is a lot of components, a lot of…emotional and psychological, not to mention just the physical logistics." (DE 899 at 106). But although she knows there are gaps in coverage, and the parents want those hours staffed, she only writes on the monthly enhanced coordination report that a parent is dissatisfied with PDN if that parent wants to switch agencies. (*Id.* at 104). As I examined dozens of monthly reports, I found that pattern to be the norm. In the comments section of a report, it would state "three out of five shifts covered. Parents satisfied with PDN." The monthly reports do not accurately portray the extent of the failure.

The Care Coordinators are limited in what they can accomplish. Vanessa Alpert, a nurse care manager with Sunshine Health, has a caseload of 15 children, with 13 at Sabal Palms. She says that when she has a problem with staffing she just continues to call agencies until she finds one willing to take on the case. And she is honest with families about the difficulties they can expect in PDN staffing. "Q: And this scares some parents right? A: I think, maybe it does." (DE 899 at 55). And like Ms. Buchanan, even where a patient with 24/7 nursing had three open shifts, she reported that the parents were content with services. (*Id.* at 59).

Not only do the monthly EEC reports fail to identify problems, but also the Care Coordinators lack authority to address the issue. The Care Coordinators work for the managed care companies responsible for delivering *all* necessary services. The managed care organizations have in turn contracted with the home health providers to supply PDN. But lacking a mechanism to require performance, the Care Coordinators simply continue to call the agencies trying to get staffing. They then offer families the opportunity to change agencies without any assurance that things will be any better. If the parents choose not to take the Hobson's Choice[31] of changing agencies, nothing more is done. "Q: So in that instance you would not get your supervisor involved? A: There would be no reason to. So, no." (DE 899 at 158).

2. Failure to Inform.

There is a widespread failure to affirmatively inform families that they have alternatives to placing their children in a nursing facility. It is not subject to any real dispute that

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[31] A "Hobson's Choice" is a free choice in which only one thing is actually offered. The most well-known Hobson's Choice is: "I'll give you a choice, take it or leave it," wherein "leaving it" is strongly undesirable.

institutionalization should be the option of last resort. Witnesses on both sides of this case readily attested to this. Therefore, providing information to families about real and viable alternatives to institutionalization is the first step in ensuring that the Institutionalized Children are residing in facilities only because they need to be, or because their families made a knowing decision regarding their placement there.

Testimony at trial was replete with examples of parents and caregivers being given no information or misinformation, as set forth in the family narratives above. (*See also* DE 912 at 283-84) (Testimony of State witness Brenda Legge, representative from Sabal Palms, who said that she felt parents are in need of additional information); (DE 894 at 38) (Testimony of State witness Elvira Vicente, a mother of a medically complex child residing at Kidz Korner, who said that no one has ever discussed housing options or other supports that might be available to her despite the significant housing challenges she faces); (DE 894 at 53-54) (Testimony of State witness Beatrice Soliz, guardian to a medically complex granddaughter, who said that no one had ever mentioned the option of a group home for her granddaughter, but that her perception was that group homes would be less "homey or family oriented"); (DE 894 at 63-64) (Testimony of State witness Jeffrey Keys, a father of a medically complex daughter, who said that he did not know anything about group homes, but that his perception was that moving her to such a place would be "devastating" for her and result in his daughter being "made more as a number and get lost in the shuffle.").

3. *Transition Planning and Barriers.*

Sending a child home from a nursing facility requires several things to happen to get the family prepared: They need equipment. They need to be trained. They need nursing lined up. They need to make arrangements for schooling and PPECs and therapies. In listening to the families of medically complex children testify at the trial, it was evident that the "transition planning" process at the nursing facilities is fraught with hurdles that should not exist. Families were sometimes discouraged or faced pushback. Sometimes they were provided with inaccurate information about the suitability of their home environment.[32] Families were also confused about how to express to facility staff that it was their preference to care for their children at home. They often felt ignored. It is unclear when transition preparations begin in earnest. The State suggested that to the extent there was uncertainty, it was because the parents had not made "formal" requests, but there was no indication that anyone ever explained to families what such a formal request looked like, what form it took, or to whom it needed to be communicated.

Another significant barrier to transitioning children out of facilities is training. A common theme of the families who testified was that they were frustrated with this aspect of the discharge process in that the scope, parameters, and structure of the training process were never fully explained. There is no organized protocol at the institutions, no well-articulated "exit plan" (as one parent put it), and no understanding of what is required before parents are deemed to have achieved

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[32] In Caden Amore's case, for example, the fact that the family resided in a one-bedroom apartment was a frequent topic of concern when they discussed bringing Caden home. It was raised as early as 2018, when Ms. Newton first began having conversations about releasing Caden from Kidz Korner. For years, Caden's parents were led to believe that they needed a bigger home, only to find out later that this was not true. (DE 906 at 65-66).

adequate proficiency with operating the medical equipment that their children will utilize in the home setting. Moreover, there was a lack of consistency with respect to who conducted the trainings and the scheduling of sessions. Indeed, Dr. Carolyn Foster, whose testimony I'll describe in detail later, confirmed that it was evident from her interviews with staff during her facility visits that training is a problem.

4. Reporting Mechanisms and Tools for Data Collection

The failure of Care Coordination is not just at the individual care coordinator level. Florida should do more to ensure that proper Care Coordination is delivered. (DE 909 at 155). Florida's data collection about Care Coordination does not allow the State to have a comprehensive picture of Care Coordination, such as who is providing and receiving Care Coordination and what types of Care Coordination are being provided. (*Id.* at 154-55). Although Florida's managed care plans have their Care Coordinators complete ECC reports that are then submitted to the State, those reports are not currently formatted in a way that would allow for proper data analysis. (*Id.* at 153-54). Instead, they have comment boxes where a care coordinator can provide additional information, which would be useful in terms of understanding an individual child's circumstances, but not for determining overall trends for the entire population.[33] (*Id.*). Without reporting mechanisms that show gaps in services, AHCA is unable to enforce the terms of its contracts requiring the managed care organizations to provide *all* necessary services.

C. <u>iBudget Waiver Services: Waitlists</u>

The iBudget waiver program is a home and community-based waiver aimed at providing services for people at risk of institutionalization. (DE 909 at 69, 140-41). Florida received permission from the federal government to implement the iBudget waiver program, allowing Florida to develop programs to prevent institutionalization.[34] (*Id.* at 63, 140). Florida's iBudget waiver program is available for people with intellectual or other developmental disabilities, aged 3 or older. (*Id.* at 141). Children with medical complexity are covered under the iBudget waiver program if they are over the age of three and have developmental disabilities, which many of the children at issue in this case do. (*Id.*). AHCA has designated the Agency for Persons with Disability to administer the iBudget waiver. (*Id.* at 141-42). The Agency for Persons with Disability determines whether someone is eligible for the iBudget waiver, and if so, the person is placed on a waiting list. (*Id.* at 142). A person who is deemed eligible is assigned a category, with Category 1 being the crisis level and Category 7 being for children. (*Id.* at 143). Lorena Fulcher, the Deputy Director of Operations for the Agency for Persons with Disabilities described the categories as

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[33] AHCA controls the format of the EEC reports and does not allow managed care plans to change the format of those reports. (DE 912 at 74). The Department of Health adds its own column to that report to capture PDN gaps from Sunshine Health. However, the Department of Health has to remove that column from the report prior to sending it to AHCA because AHCA will not accept the report with the extra data.

[34] The Medicaid Act allows states to request a waiver of certain requirements to offer a variety of community-based services to individuals with disabilities. 42 U.S.C. § 1396n(c). The iBudget waiver is a Home and Community-Based Services Waiver (HCBS) program under section 1915(c) of the Social Security Act. (DE 840, Pretrial stip., Section VI, ¶ 79).

follows: Category 1 is for individuals in crisis, defined as those who are homeless, a danger to themselves or others, or their caregiver is unable to provide care and there are no other available supports or services; Category 2 is for individuals who turn 18 while in the child welfare system; Category 3 is for people with significant physical or behavioral needs; Category 4 is for individuals with aging caregivers; Category 5 is for individuals getting ready to transition from school; Category 6 is for individuals over the age of 21 who do not meet the criteria for any other category; and Category 7 is for individuals under the age of 21 who do not meet the criteria for any other category. Ms. Fulcher explained that there is no waiting list for individuals in Categories 1 and 2. (DE 896 at 69-71). Dr. Bachman described children in Category 7 as being the last to be enrolled in the program. (DE 909 at 143). Florida currently has about 20,000 people on the waiting list, including about 500-800 children with medical complexity, and it can take years to get off the list. (*Id.* at 143, 145).

Once a person makes it off the waiting list, the iBudget waiver program provides a variety of services—including environmental accessibility adaptations (*i.e.*, home modifications to support physical accessibility); respite care; durable medical equipment and consumable medical supplies, including vehicle accessibility adaptations and portable ramps; and certain transportation services – that make it possible for the person to live in the community. (DE 840, Pretrial stip., Section VI, ¶ 86; DE 909 at 70-71). For children with medical complexity, such services may include installing a wheelchair ramp, widening a doorway, and providing transportation that can accommodate a wheelchair. (DE 909 at 88). The iBudget waiver covers services that are not covered under EPSDT. (DE 897 at 136).

The evidence presented indicated that children with medical complexity are waiting for iBudget waiver services, which prevents children from accessing nonmedical services, such as home and vehicle modifications, that are specifically designed to help people with disabilities live in communities. Some of the children on the waiting list currently live in nursing facilities.

Dr. Bachman explained that 500-800 children with medical complexity are currently on the iBudget waiver program waitlist, including 19 children living in nursing facilities. (DE 909 at 145; DE 912 at 62; DE 840, Pretrial stip., Section VI, ¶ 90). Dr. Bachman said that the wait list reflects a tremendous gap in service availability because the children on the waiting list have already been determined to be eligible for the iBudget waiver. She also said that some children will have to wait years to make it off the waiting list, meaning that they will wait years for the very services that promote home and community-based care. (DE at 145-46). Because children with medical complexity are on the waiting list, this indicates that Florida's Medicaid program does not sufficiently serve those children in the community. (*Id.* at 146). Additionally, Ms. Fulcher testified that she was not aware of any child in a nursing facility who was unable to transition to the community because they were on the iBudget waiting list. (DE 896 at 78).

However, Ms. Fulcher said that "we have laws that allow us to enroll any individual who is in an intermediate care facility or a skilled nursing facility who is eligible for iBudget waiver. If they wish to leave that institutional setting and receive iBudget waiver services, they don't go on a waiting list. They are immediately prioritized for waiver enrollment." (DE 896 at 75-76). She described this as the "transition proviso." (*Id.* at 76). If that is true, it does not explain why there are children living in nursing facilities who are still on the waiting list. It may reflect that despite this transition proviso, there is an administrative problem in ensuring it is being utilized. For children with medical complexity already living in a home or community setting who are on the waiting list, which far outnumber the children living in nursing facilities on the waiting list, receiving the iBudget waiver will help support keeping them in homes or communities, reducing the risk they will enter a nursing facility.

D. Medical Foster Care Program: Eligible Children are Institutionalized

Florida's Medical Foster Care program is a community-based service for children with medical complexity that enables these children to live and receive 24-hour care in licensed foster homes with foster parents. (DE 909 at 128; DE 840, Pretrial stip. VI, at ¶ 53, 54, 55). Because medical foster homes are family-based settings, they are less restrictive than nursing facilities, and one of the program's goals is to eliminate the need for long-term institutional care for its children. (DE 840, Pretrial stip. VI, at ¶¶ 59, 61). In fact, it is a policy of the Department of Children and Families ("DCF"), which manages the foster care system, that its children with complex needs be placed in the least restrictive environment medically possible, and that when a child must be placed in a nursing facility, that they will work to transition the child to a less-restrictive environment. (*Id.* at 60).

Although Florida has a voluntary placement program that allows parents or guardians of children with medical complexity to temporarily place their children with foster parents without relinquishing custody (up to 180 days), Medical Foster Care requires that parents or guardians relinquish custody of their children. (DE 909 at 128-29).[35] Medical Foster Care requires collaboration between the Department of Health and the Department of Children and Families. (*Id.*). The Department of Health, via CMATs, is responsible for determining a child's eligibility for Medical Foster Care, which also makes the child eligible for Medicaid. (*Id.* at 129).

After eligibility is determined, DCF begins the process of trying to place the child with a foster parent. (*Id.*). Until that happens, a child may wait in kinship care, a regular foster home, or an institution (*i.e.*, a nursing facility). (*Id.* at 135-36). Foster parents are trained by the Department of Health to care for the children once placed. (*See* DE 976-1 at 496). Medicaid reimburses medical foster parents up to $76.99 per day to render medically necessary services for the children in their care. (DE 840, Pretrial stip., Section IV, ¶ 66). AHCA is responsible for setting the Medicaid reimbursement rates for Medical Foster Care parents and for recruiting them. (*Id.* at ¶¶ 63, 66).

The evidence presented at trial showed that children with medical complexity, including some in nursing facilities, are in the State's custody but have not been placed with Medical Foster Care parents.[36]

Dr. Bachman explained that there are children in nursing facilities who are on the waiting list for the Medical Foster Care program. (DE 909 at 136). Joni Hollis, the Chief of Medical and

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[35] As to this issue, at the summary judgment stage, I ruled in favor of the State in part, and found that requiring Florida to change its Medical Foster Care program to allow parents or guardians to place their children with medical complexity in Medical Foster Care without relinquishing custody to Florida would be a fundamental alteration of the program. (DE 882).

[36] As of February 15, 2023, there were 176 medical foster homes in Florida with a total capacity of 477 beds. Of these, 315 beds were filled. (DE 840, Pretrial stip., VI, at ¶ 71). Thus, there is availability.

Health Services at Florida's Department of Health, is in charge of the CMATs and the Medical Foster Care program. Ms. Hollis explained that there are approximately 40-50 children who have been deemed eligible for the Medical Foster Care program and are awaiting placement at any given time; at the time of trial, there were 30. (DE 894 at 259-60). She also confirmed that at least seven children in nursing facilities were in the State's custody. (*Id.* at 255). Dr. Bachman opined that the fact that there are children currently living in nursing facilities who are awaiting Medical Foster parents reflects an access-to-care issue. (DE 909 at 136).

In the spring of 2022, Ms. Hollis submitted a budget request for recruitment of Medical Foster parents and the legislature provided $570,000 for 2022/2023, with $400,000 for each following year. (DE 894 at 226). In her budget request, she cited that there was a shortage of Medical Foster parents and sought funds to market the Medical Foster Care program to recruit more parents. (*Id.* at 261-62). Since receiving the funding, the agency has contracted with a marketing and advertising vendor to conduct a media campaign (social media and streaming television), established a Medical Foster Care online portal for people to register their interest in the program, and developed a brand and logo to be used on "swag" for various stakeholders. This initiative is commendable and hopefully will help eliminate the backlog.

Ms. Hollis's testimony supports Dr. Bachman's recommendation that recruitment is critical. Although they have started the process of increasing recruitment efforts, Florida has offered no evidence that it is working to match specific children now in nursing facilities with parents.

VIII. THE STATE'S DENIAL OF ACCESS TO SERVICES IS RESULTING IN UNNECESSARY INSTITUTIONALIZATION

Florida's pediatric nursing facilities are segregated settings. The State of Florida is obligated to provide adequate community-based services to children with complex medical needs who rely on Medicaid. The United States presented substantial evidence of the failings of Florida's delivery of services to these children.

As a result of gaps in the State's administration of its Medicaid program, families of the Institutionalized Children have resorted to placing their children in nursing facilities so they can receive needed services. This pattern of institutionalization is undue. And the families of medically complex children residing at home are filling in service gaps themselves, which places their children at risk of institutionalization should their families be unable to sustain their children's care while also working and caring for other family members. The Supreme Court in *Olmstead* made clear that unnecessary institutionalization is discrimination by reason of disability because "[i]n order to receive needed medical services, persons with . . . disabilities must, because of those disabilities, relinquish participation in community life they could enjoy given reasonable accommodations, while persons without disabilities can receive the medical services they need without similar sacrifice." 527 U.S. at 601.

Specifically, and as set forth in detail above, Florida has failed to provide PDN to children with medical complexity and also failed to provide consistent and effective Care Coordination to ensure that these Medicaid programs are addressing these children's complex needs. Although Florida has other programs that can assist with the care of children with medical complexity in community settings—the iBudget Waiver and Medical Foster Care—the programs have years long waiting lists that prevent the children from accessing them.

The problems are compounded by Florida's failure to track and analyze data that would help identify gaps in services. Moreover, the State fails to provide sufficient monitoring and enforcement of contractual compliance. Finally, parents and guardians of children with medical complexity are not provided transition and discharge planning at regular intervals as required by law. As a result, many parents and guardians of children living in nursing facilities are not being provided with information about the available services provided to children with medical complexity at home. The complicated structure of Florida's Medicaid program is no excuse for a lack of accountability; indeed, it suggests that Care Coordination and oversight, monitoring, and accountability are even more important.

I find 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. I am 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. Whether the State has violated the ADA's integration mandate with respect to its provision of Medicaid services turns upon whether the elements of *Olmstead* have been established. I conclude that they have been, and I will explain why in the sections that follow.

IX. APPLICATION OF THE *OLMSTEAD* ELEMENTS

A. Appropriateness

The ADA prohibits discrimination against "qualified individual[s] with a disability." *Olmstead*, 527 U.S. at 602 (quoting 42 U.S.C. § 12132) (alteration in original). People with disabilities are "qualified" if, "'with or without reasonable modifications to rules, policies, or practices,'" they "'mee[t] the essential eligibility requirements for the receipt of services or the participation in programs or activities provided by a public entity.'" *Olmstead*, 527 U.S. at 602 (quoting 42 U.S.C. § 12131(2)) (alteration in original). Under the Supreme Court's analysis of these statutory provisions, community placement is considered "appropriate" for individuals if they could live in the community with sufficient services for which they would be eligible. *See id.*

1. *Applicable Law – Medical Appropriateness*

Before I set out my factual findings in support of my conclusion that the Institutionalized Children are appropriate for community living, it is necessary to resolve what "appropriateness" means. The State takes the position that a child's actual, real-world community setting should govern the determination of whether they are "appropriate" for community placement. Thus, the State argues that it is a mistake to examine this issue by reference to the child's medical condition alone, and not by reference to the home where the child will actually live. The State repeatedly raised issues concerning the size and suitability of the families' homes, suggesting that they are far from ideal living situations, making it unsafe, unhealthy, or unsanitary to provide care in the home environment. (*e.g.*, Testimony of Dr. Greissman, DEs 896, 911). And the State suggests that because sometimes the children's home environment is not suitable to their needs, the children should not be found "appropriate" for community living.

This reasoning is flawed. It involves an evaluation of barriers that might exist to home placement, which are outside the families' control but often *within* the State's control. For instance, consider a situation in which a child's home could be made more suitable for them through the State's provision of services through the iBudget waiver program, but the waitlists for that program render it useless to many families who need it. The State should not be permitted to deny access to that program, and then when faced with a discrimination lawsuit seeking to expand access, turn around and argue that the plaintiff cannot prove an element of the discrimination case. It would defeat the purpose of the law if a defendant could use the effects of its discriminatory conduct against a plaintiff who is suing for discrimination.

To take practical issues into account in evaluating appropriateness, as Florida suggests, would quickly render the analysis unmanageable and overly subjective. Medical professionals have expertise in evaluating the medical status of the child – not the environment of a home or the dedication of a parent. It runs a real risk of rendering the analysis unfair, in that inevitably, families with less means who live in smaller homes are more likely to find that their children are not appropriate to live in the community.

The facts of *Olmstead* illustrate how the State misunderstands the appropriateness inquiry. The defendant in *Olmstead* sought to discharge one plaintiff in the case to a homeless shelter, which she rejected. In holding that E.W. was entitled to community integration, the Supreme Court did not scrutinize what other "specific" settings the plaintiff could possibly have been discharged to. The record on appropriateness consisted of evidence relating to whether institutionalization was necessary for the plaintiff's medical treatment, and whether she would benefit from receiving habilitation services in a community setting instead. Brief of Respondent at 8, *Olmstead v. L.C.*, 527 U.S. 581 (1999), No. 98-536, 1999 WL 144128, at *7-8.

The safety and suitability of the community setting at which a medically complex child will receive services is unquestionably important. However, the appropriateness inquiry does not require an inquiry into the safety of each person's potential placement. *See, e.g.*, *Olmstead*, 527 U.S. at 601-02; *Frederick L. v. Dep't of Pub. Welfare*, 364 F.3d 487, 493 (3d Cir. 2004) ("*Frederick L. II*") (appropriateness not in dispute where district court found that one-third of institutionalized appellants were qualified for existing community-based services, without discussing whether specific settings were appropriate); *Mississippi*, 400 F. Supp. 3d at 575-76 (individuals were appropriate for community-based services such as supported housing, but not based on evidence that specific non-institutional settings were available to specific individuals); *Cruz v. Dudek*, No. 10-23048-CIV, 2010 WL 4284955, at *13 (S.D. Fla. Oct. 12, 2010) (discrimination occurred where plaintiffs were "able to live in their own home[s] with adequate support services" but could not obtain adequate services); *Disability Advocates, Inc. v. Paterson*, 653 F. Supp. 2d 184, 257-58 (E.D.N.Y. 2009) ("*DAI II*"), *vacated on other grounds sub nom. Disability Advocates, Inc. v. N.Y. Coal. for Quality Assisted Living, Inc.*, 675 F.3d 149 (2d Cir. 2012) (not necessary to assess specific services each class member would need in the community to establish appropriateness for community-based housing).

Therefore, in interpreting what "appropriateness" means, I find that it means *medical* appropriateness.

Dr. Carolyn Foster testified as an expert for the United States. She is among the most renowned pediatricians in the United States specializing in the medical care needs and related services for children with medical complexity.[37] Her testimony, which I credit, supports my

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[37] Dr. Foster is an expert clinician and researcher in the medical care needs and related services for children with medical complexity. (DE 906 at 11). Dr. Foster is a member of the Executive Committee of the American Academy of Pediatrics' Section on Home Care, and the Medical

interpretation of "appropriateness." (*Id.* at 157-159). In her practice, she viewed the medically complex child's home environment as irrelevant to the determination of whether the child was medically stable enough to live in the community with services. Moreover, she viewed medical stability as a matter for doctors to decide, and she perceived preparedness of the family (*see infra* regarding readiness as it pertains to the "Non-opposition" element of *Olmstead*), and suitability of the home, as matters related to discharge planning and Care Coordination. And to take it one step further, Dr. Foster did not view as obstacles many of the factors which the State suggested could make a home unsuitable at the discharge planning stage. It is not necessary for a medically complex child to have their own bedroom, for instance. It is also not necessary for a medically complex child to live in a two-parent home. It is also okay for a medically complex child to reside with young siblings in the house. All of these variables are capable of being safely managed. None of these things should pose obstacles in the transition planning process, and more broadly, none are even relevant to *medical* appropriateness.

As the evidence in this case made clear, these families face barriers to transitioning home, but those barriers can be overcome by the provision of services and support, and/or they can be managed with preparation and training. Medical appropriateness does not require an assessment of those barriers; such matters may be addressed in subsequent phases.[38]

2. The Children Are Capable of Community Living

Children with "medical complexity" have a complex chronic condition that affects multiple parts of their bodies or organ systems, such as the brain, heart and lungs. Because of these conditions, they have disabilities, and they typically rely upon medical technology to assist them

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Advisory Board for the State of Illinois Title V program, which manages that state's pediatric home health nursing program. (*Id.* at 127-28). In addition to her medical degree, Dr. Foster holds a Master of Science in Health Services and is a professor of pediatrics at the Northwestern University Feinberg School of Medicine. (*Id.* at 122, 125). She has published 15 peer-reviewed manuscripts on moving children with medical complexity from hospitals to community-based settings and on the quality and experience of care delivery in the home for medically complex children. Besides her research, Dr. Foster has extensive clinical experience. Dr. Foster co-directs a clinical program that serves about 200 children with medical complexity in outpatient clinic and hospital settings. Her work regularly involves determining community-based service needs and prescribing and ordering community-based services for her patients.

[38] I note that the focus of the United States' evidence at trial was the provision of services for children to be cared for in their family homes. However, various witnesses from time to time made mention of group homes as another suitable option for community-based placement for the Institutionalized Children. The State's focus on the home within the context of rebutting "Appropriateness," and its emphasis on the fitness and/or suitability thereof, is misplaced in the sense that community living does not have to be the child's *home*. It can be any other integrated community setting "that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible." *Stiles v. Judd*, No. 8:12-CV-02375, 2013 WL 6185404, at *2 (M.D. Fla. Nov. 25, 2013) (quoting 28 C.F.R. Part 35, App. B (2011)). That their actual homes may not be "appropriate" for their care does not mean that there is not a more integrated setting, something short of institutionalization, that would be.

in eating, drinking, moving, and breathing.[39] (DE 906 at 123). This is a rare segment of the population, comprising less than 1% of pediatric patients.[40] (DE 906 at 127). Despite their wide-ranging diagnoses, children with medical complexity experience similar outcomes across their organ systems. Therefore, they tend to have stable, predictable needs, and care plans can be created for them.

Having concluded that medical appropriateness is the relevant inquiry, I further conclude that the evidence established that all of the Institutionalized Children, despite their challenges, are indeed capable of community living. Dr. Foster and the two other United States experts, working as a team,[41] set out to answer the question of whether the children currently residing in pediatric nursing facilities in Florida would be appropriate to receive those services in a home or community-based setting. To answer this question, she and the other experts conducted an individualized review of the medical records of all 139 Institutionalized Children. They also toured all three pediatric nursing facilities in Florida to assess the care the children were receiving.

a. Review of Medical Records and Tours of Facilities

The United States' three experts developed a standardized methodology for reviewing the Institutionalized Children's medical records. There were 139 medical files, comprising thousands of documents. The goal was to understand each child's individualized care needs by reference to their diagnoses, functional status, and details of their care plans. The doctors could then assess whether those needs could be met in a home setting. (DE 906 at 163-64). The experts reviewed Florida's policies to understand what services were offered to the Institutionalized Children in the community. The State's Medicaid program already offers in-home nursing and durable medical

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[39] The most common technology seen across the population of medically complex children is the feeding gastrostomy tube, or G-tube, for those who have trouble swallowing. The G-tube is placed into the stomach through a small incision on the abdomen and the child can receive supplemental or all nutrition that way. Another common device is a tracheal/tracheostomy tube, or "trach," which is a short tube inserted through an incision in the neck, and this helps them to breathe. When a child also needs a breath to be taken for them, he or she uses a ventilator, which does that. The ventilator is a small, portable machine.

[40] Thus, a typical pediatrician might have a panel of two thousand patients and only see a dozen or so medically complex children. Dr. Foster has cared for thousands of medically complex children. And her patients are comparable to the broader population of medically complex children across the country. Importantly, this renders her opinions relevant to the medically complex children at issue in this case, even though she did not personally treat or care for them. *See e.g.* DE 906 at 150: "[T]here are descriptions of the patients in the literature that I can compare [with] my patient panel" to confirm that her patients reflect the broader population; and also she "actively work[s] with others nationally," who specialize in this area, providing further bases for comparison.

[41] The three United States experts divided the medical files up for review between them, and they drew their own individual conclusions, which all aligned with each other. However, it was only necessary for one of them to testify about each issue they were asked to address, namely "appropriateness" and "non-opposition." Dr. Foster handled the former and Dr. Houtrow the latter. Dr. Ehlenbach testified as a rebuttal witness to the States' expert, Dr. Griessman.

equipment, services that are typically made available in homes and communities across the country. (DE 840, Pretrial stip., VI, ¶¶ 23, 34-35).

During the facility tours, the experts observed the children residing in the facility and the care being provided there. They spoke with staff and nursing leadership at each facility along with administrators, respiratory therapists, and social workers, to learn how the facilities structured medical and social services for the children, including routine staffing and monitoring as well as the facilities' preparation for and handling of emergencies. The experts asked questions about the staff's interaction with families, their experience in providing care to medically complex children, and the degree of oversight provided by physicians, among other topics.

One area of focus in both the record review and the facility tours was the predictability and frequency of each child's care, as these tended to be proxies for a child's medical stability. Dr. Foster explained that she looked for indications of how often orders were changed. She testified that the lack of change orders in the Institutionalized Children's medical records was indicative of their general medical stability. Dr. Foster further looked at physician oversight and observed that at the nursing facilities, it was not extraordinary. There is a doctor on site only occasionally, making rounds. Therefore, the Institutionalized Children did not appear to be experiencing significantly more interaction with physicians than children in a home setting.

Another area of focus was whether the child was at risk for a medical emergency and, if so, whether they could be safely planned for in the home setting, as well as any other indications of a potential rapid change in health status that would make living at home unsafe. She sought to understand how the institutions handled emergencies when they occurred.

An additional area of focus was the ratio of nurses to patients at the facilities, and the quality of nursing care. The Institutionalized Children and the medically complex children residing at home both receive nursing care. But the care at home is generally one-on-one. In the facility, the ratio tends to be higher. Moreover, the level of nursing care at the facilities and at home is the same – the facility nurses are no better educated or better qualified or more highly skilled – both types of nurses are trained to accommodate the long-term daily care of kids who are medically complex but stable.[42]

One aspect of Dr. Foster's testimony that was particularly concerning was that during her facility tours, she observed some children who she was surprised had qualified for institutional level care. The severity of their conditions did not seem to warrant it.

b. Expert Opinion

Dr. Foster concluded that all 139 Institutionalized Children could be treated in a home or other community-based setting, if appropriate accommodations were made. In Dr. Foster's experience, the needs of the children at issue in this case did not differ greatly from the medically fragile children that she routinely sees in her own practice, who reside at home with their families notwithstanding the high level of medical care and oversight that they require. The technologies

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[42] Dr. Foster noted one exception in terms of the potential for access to more or a higher level of care for the Institutionalized Children, and that was the presence on site of respiratory therapists. But in her view, this did not render the institutional setting better or more suitable, overall. (DE 906 at 194-95).

used in the nursing facilities she observed are the same as that used in the home environments of the kids she is accustomed to treating. The medications are of the same complexity. None of the patients' care needs were above and beyond what she typically observes in her practice, and none of her patients are institutionalized.

Moreover, the emergencies that she saw documented in the medical records of the Institutionalized Children are the same sorts of emergencies that she knows parents to be capable of managing at home, based upon her experience. In sum, the pediatric nursing facilities in Florida are not providing acute level care; a trained parent can do everything the caregivers in nursing homes are doing.

3. Home is Best

The Institutionalized Children can benefit from living in the community, as growing up in a family environment allows for daily social interaction with parents and siblings, as well as developmentally enriching activity such as play and exploration, while long-term residence in institutional nursing facilities has unhealthy ramifications for children without added medical benefit. (*See generally* Testimony of Dr. Foster, DE 906, and Testimony of Dr. Ehlenbach, DEs 899 and 913.)

The vast majority of children with medical complexity live in their family's homes. (DE 906 at 143). This is because "a child is best cared for in their home environment." (*Id.*). There, they experience the "most rich social, behavioral and physical care." (*Id.* at 143-44).

Dr. Foster discussed a clinical report of the American Academy of Pediatrics regarding out-of-home placement guidelines for children and adolescents with disabilities. The report contains "best practice guidance for pediatricians" and was authored by the Council of Children with Disabilities. Dr. Foster confirmed that this guidance is consistent with her own experience and professional opinion on this topic. (*Id.* at 149). The guidance is as follows:

> Children and adolescents with significant intellectual and developmental disabilities and complex medical problems require safe and comprehensive care to meet their medical and psychosocial needs. Ideally, such children and youth should be cared for by their families in their home environments. When this type of arrangement is not possible, there should be exploration of appropriate, alternative non-congregate community-based settings, especially alternative family homes.
>
> Well-established factors that contribute to healthy development that are embedded in most families are missing in even the best congregate care settings. Factors inherent in congregate care that distinguish it from family and render it potentially harmful to children include: (1) a large ratio of children to caregivers; (2) absence of a primary caregiver for each child; (3) . . . turnover of caregivers; (4) inferior cognitive, linguistic, and social-emotional stimulation; . . . (5) regimented schedules and a lack of spontaneity in child-adult interactions; and (6) limited peer-to-peer interaction.

(DE 906 at 145-47). It is clear that there are profound psychological and emotional benefits that medically complex children can derive from residing at home. Thus, Dr. Foster would not endorse the notion of a child living in a nursing facility for *medical* reasons. The only exception to her endorsement would be the deference and respect that is owed to the choice of an individual family. Indeed some families do choose institutionalization, for various reasons. We heard from several of them. And there is no question that their decisions should be honored and supported.

4. The Court's Site Visit to Kidz Korner

On May 16, 2023, during the trial, I visited The Kidz Korner nursing home in Plantation, Florida. I requested to do so because I perceived that it might be helpful for me to see one of the facilities in person. Counsel for both Florida and the United States readily agreed. My observations have provided me with useful context and aided my understanding of the testimony I heard regarding the emotional and psychological impacts of institutionalization.

During the tour, I was accompanied by a representative of each Party. A manager from the facility served as our guide. Since we did not take a court reporter on the visit, we agreed in advance that no questions would be asked.

We entered the lobby of a two-story building with one wing dedicated to children. (The other is devoted to geriatric care, which we did not visit.) After passing through the lobby, we encountered a large open area with a number of children and staff, most of the children in wheelchairs, several with breathing assistance. Most were watching a screen playing "Baby Shark." Some walls were painted with colorful murals.

Past the open area and on both floors were a series of rooms generally with two children per room. Most of the children in those rooms appeared to be sleeping, and the rooms seemed clean with an institutional setting similar to the feel of a hospital room. The beeping and alarming of various types of machines could be heard.[43]

As I walked the long hallways, I observed many children alone in rooms, usually with TVs on, and no caregiver present. I also observed several infants in crib enclosures attached to medical equipment. The most fragile babies were located in a larger room, together, with nurses there monitoring. Several children were in a room receiving therapy; it appeared they were engaged in tactile exercises of various sorts. Our guide explained that the children rotated in and out of the therapy areas throughout the day. He also said that a few children attend school off site.

During my visit, I did not see any family members. That may have been because my visit

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[43] Reflecting back on the trial testimony, many of the parents and caregivers talked about these sounds occurring in their homes. Many also said that even without the alarms, they have become attuned to the particular patterns of their own children, their breathing rhythms, sounds, nonverbal communication signals, movements. *See, e.g.*, Testimony of Julie Pagano: "[I]t's just a constant sound."; "I have lived with them for ten years. They're not alarms to me anymore."; "I'm used to the sound of the air circulating."; "the ventilator . . . won't always alarm"; the "[m]achines are . . . not humans." (DE 910 at 89-90); *see also* Testimony of Eve Harris: "With me being around [Jeffrey] a lot, I can hear . . . different breathing pattern[s]" which the nurses could not detect as well. (DE 907 at 18). This just serves to underscore the benefits of caring for medically complex children at home.

was in the afternoon, during working hours. But regardless, the observation served to reinforce the idea that these kids are segregated from the community while they are institutionalized.

One of the State's witnesses, Dr. Greissman, testified that the chronic care facilities like Kidz Korner "are not that bad," in part because they are "colorful places with people around," with painted murals, and the like. (DE 896 at 289). I appreciate that, and I observed the murals. But brightly painted walls don't make the nursing facility any less an institutional, isolated setting for the children who reside there. Dr. Greissman also said that the kids are constantly surrounded by people, they are never alone. But, of course, it is possible to be in the presence of people yet still be lonely. As I reflect on my personal observations at Kidz Korner, I was struck by Dr. Ehlenbach's remark during her rebuttal testimony. She said: "[W]hile they [the children] may have been surrounded by people, they were very alone. They were lonely." (DE 913 at 18).

5. *The Children's Eligibility for Community Based Services*

As an independent and alternative additional ground for a finding of appropriateness, I note that if a medically complex child is already deemed eligible for community-based services, then it follows that the child has already been deemed capable of living in the community with access to those services. The United States proved that many of the medically complex children who are residing in institutions have been deemed eligible by the State and its managed care plans for community-based services and programs, including PDN, the iBudget waiver program, and Medical Foster Care.[44] Moreover, some of the Institutionalized Children lived in the community while receiving private duty nursing prior to their institutionalization. *See, e.g.*, USA Exs. 2557-60, 5223, 5318, 5195, 2155, 2283, 1388, 2058. Christian, Dondrea, and Jeffrey are all examples. These children were institutionalized solely because the State failed to provide their families with adequate PDN staffing, despite that they qualified for the medically necessary service.

6. *The State's Counterarguments*

The State had a number of responses to the United States' proof regarding the appropriateness element of *Olmstead.* The State argued: (1) institutionalization is a better, safer, or more practical option for some kids and for some families; (2) many medically complex kids lack suitable homes to be discharged to; and (3) the families who do choose to place their children in nursing homes deserve to have their choices respected. I'll address these in reverse order.

I agree, and this is not in dispute, that when a family chooses institutionalization, that choice should be honored. This is a personal and highly sensitive decision, dependent upon the unique circumstances of each individual family.[45] But I do not agree that because some families

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[44] Likewise, the At-Risk Children have been deemed eligible for community-based services.

[45] *See* Testimony of Elvira Vicente: "[M]y kid [Emily] is [in] the best place if she stay[s] [at] that place that I mentioned [Kids Korner], not because I don't love her, not because I don't want her to be with me; it's just because I know that [at] that place, they are taking care of her well." (DE 894 at 36); Testimony of Marcelia Dalmous: describing difficulty with ability to care for her son while residing in the Bahamas (DE 910 at 230-31; 239); Testimony of Marilyn Harrigan: the fact that Sabal Palms has kept her 19-year-old grandson "clean" and alive all these years renders the care he is receiving at Kidz Korner satisfactory enough, in her view; she viewed

choose nursing home placement, this somehow detracts from the idea that, broadly speaking, virtually all children *could* appropriately be served in the community. I also reiterate that the families who make the choice to place their medically complex children in nursing facilities should do so only after being informed of all the alternatives (and community placement must be an option that is actually *viable,* meaning there would be services in place to support it).

The State also argued, however, that in some instances, institutionalization is a better option. Its expert witness on this subject was Dr. Allan Greissman, whose testimony I reject. He articulated a series of opinions which I found to be problematic.

For instance, he testified that some children would derive no benefit at all from familial interaction in a home setting, such as children who were described as being in a "persistent vegetative state," or "neurologically devastated." The implication was that these children may as well remain institutionalized. To me, this is an unpalatable assessment and conclusion. For one, both Dr. Foster and Dr. Ehlenbach took issue with Dr. Greissman's use of the term "persistent vegetative state," as this phrase is not uniformly described in medical circles. The State defined it as having complete unawareness of self or environment, no language comprehension, and no evidence of responses to stimuli. Dr. Foster testified, however, that this definition is inconsistent with medical research, in that oftentimes MRIs show more brain activity than is presumed to exist based upon an outward examination of a patient. But moreover, the United States' experts were clear that even the kids ostensibly falling into this category *can* benefit from one (or just a few) loving caregivers and the consistency that this provides, as opposed to a series of shift workers in institutions.

Dr. Greissman further suggested that institutionalization may be more appropriate in some cases because the absence of a medically complex child at home will help the parents of that child better care for their typically developing, healthier kids. I find this decision better left to parents.

Moreover, Dr. Greissman testified that some of the institutionalized children simply cannot, or should not, be cared for at home, due to their fragility and the likely inability of parents to deal with certain emergency situations. In short, he suggested that nurses in institutions are just better at caregiving. Thus institutions are a safer environment, and this justifies maintaining some kids in nursing homes. I reject this opinion too, given the expert testimony from Dr. Foster and Dr. Ehlenbach that the Institutionalized Children are receiving no better or different care than they would at home. Indeed, Dr. Ehlenbach testified that she observed the ventilation equipment used in the facilities to be less advanced than what she has observed in use by families who are caring for their children at home. (DE 899 at 192). Moreover, Dr. Lavandosky, the Medical Director at Kidz Korner, acknowledged that a child at home with PDN has more one-on-one, direct, round-

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the constant Care Coordination meetings as an annoyance. (DE 894 at 12-13); Testimony of Beatrice Soliz*:* A grandmother and legal guardian to a medically complex granddaughter. She chose facility placement at Kidz Korner for the granddaughter because while she was caring for the child at home, her medical needs became too demanding ("She got really bad"), and Ms. Soliz is also the sole caregiver to her husband who has Parkinson's, plus she resides with and takes care of another grandchild. (DE 894 at 42-43); Testimony of Jeffrey Keys*:* Father of Emily, who has lived at Sabal Palms for 10 years, she is 13. Mr. Keys felt that he would be incapable of caring for Emily on his own, because he feels she is too medically fragile for him to feel comfortable. (DE 894 at 58).

the-clock care than a child in a nursing facility. (DE 896 at 49-50). Dr. Foster further testified that in the home setting, emergencies are fairly rare; she estimated once a year or perhaps every six months. And families are trained to be able to handle such situations until medical staff can respond. What was clear from Dr. Foster's testimony is that when an emergency does occur, the nursing home is no better equipped to deal with it than a parent at home.

These were Dr. Greissman's opinions, despite the fact that he did not examine the medical records of the children in this case, and despite the undisputed evidence that all of the institutionalized children are in that particular setting because they *are* medically stable and they do *not* require placement in an acute care facility, such as a hospital. As Dr. Foster testified, a medical doctor determines whether a child is too unstable to be discharged from a hospital. Thus, if a child is stable enough to reside in a nursing facility, he or she is stable enough to reside at home. This has been the standard nationally, according to the American Pediatrics Guidelines, since 2012.[46]

Dr. Greissman also illustrated his view of medically complex children through the use of a Venn Diagram, making generalizations about when children could or could not go home. (DE 896 at 270-71). And he divulged that his opinions were at least in part driven by a concern that this litigation would result in the closing of pediatric nursing facilities if the United States prevailed, and out of a concern that if such facilities did not exist, then hospitals, such as the one where he worked, would be over-populated with medically stable children whose families were not yet prepared to take them in. I found aspects of Dr. Greissman's testimony to be patronizing, disrespectful to parents, and oblivious to the life circumstances of many people who lack substantial financial resources.

7. Conclusion: The Institutionalized Children are Appropriate for Community Living

The facts and evidence set forth above establish the "appropriateness" element of *Olmstead* in two ways. First, in the most straightforward of ways, through evidence that many Institutionalized Children *already qualify* for community-based services, thereby supporting a finding that the State itself deemed them to be capable of community living. I have found (indeed it does not even appear to be disputed) that the State has already deemed many of the Institutionalized Children to be eligible for resources. By approving and previously allowing receipt of community services, the State's own medical professionals and specialists have demonstrated that community placement is not only appropriate, but it is possible. *See Steimel v. Wernert*, 823 F.3d 902, 915-16 (7th Cir. 2016) (if individuals have previously been approved for a public entity's community-based services, then they are appropriate for such services as a matter of law, as "the state's medical professionals have demonstrated that [community treatment] is both appropriate and possible"); *see also Radaszewski v. Maram*, 383 F.3d 599, 612-13 (7th Cir. 2004) (explaining that the fact that the young adult at risk of institutionalization had lived at home for years supported a finding that he could "handle and benefit from" community-based services); *A.H.R. v. Wash. State Health Care Auth.*, 469 F. Supp. 3d 1018, 1045 (W.D. Wash. 2016)

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[46] The governing and preeminent medical authorities in the United States, such as the American Academy of Pediatrics and the American Thoracic Society, recommend, and extol the benefits of, community placement for children with complex medical needs. (DE 906 at 143-44; DE 913 at 28).

(medically complex infants' and toddlers' authorization to receive PDN rendered their family homes the "most integrated setting appropriate" to their needs). Along these same lines, if individuals are currently receiving state services in their communities, this history of community living demonstrates that to continue living at home, with adequate services, would be appropriate. *See, e.g.*, *Radaszewski*, 383 F.3d at 612-13; *Townsend v. Quasim*, 328 F.3d 511, 516 (9th Cir. 2003); *Cota v. Maxwell-Jolly*, 688 F. Supp. 2d 980, 994 (N.D. Cal. 2010). All of the At-Risk Children whose families testified are currently receiving services, such as PDN, which enable them to live at home, even if precariously. It can hardly be disputed that this population of children is appropriate for community living (with services); they are already living in the community.

Second, the Institutionalized Children do not need to live in pediatric nursing facilities; their disabilities do not require it, and Florida could provide services that would enable community living. This was established through the expert testimony of Dr. Foster, who opined that all of the Institutionalized Children are capable of community living from a medical perspective, so long as they have necessary resources and services. Dr. Lavandosky, the Kidz Korner medical director, opined that 70% of the children currently there could live at home. In *Olmstead* cases, plaintiffs can demonstrate that they are appropriate for community living if they show that there is "nothing about their disabilities that necessitates living in" institutions, as there are services that could meet their needs in the community. *DAI II*, 653 F. Supp. at 256; *see Cruz*, 2010 WL 4284955, at *13 (discrimination occurred where plaintiffs were "able to live in their own home[s] with adequate support services" but could not obtain adequate services).

The State made no meaningful effort to rebut the conclusion that the children are *medically* stable and can be cared for in the community; rather its focus was on the interpretation of the "appropriateness" element, an issue that I have resolved against the State.

Children who are medically capable of residing in the community with resources should be deemed appropriate for community living for other important reasons too. There are undeniable psychological, emotional, and practical health benefits of community living. These benefits were repeatedly reinforced by the narratives I heard from multiple families. And the disadvantages to institutional living were strongly reinforced by my own site visit to a pediatric nursing facility. Given all this, I find that the appropriateness element of *Olmstead* is met.

B. Non-Opposition

The ADA requires that community-based services be provided to qualified individuals with disabilities who do not oppose such services. *Olmstead*, 527 U.S. at 602, 607 (citing 28 C.F.R. § 35.130(e)(1)). The United States has proven that the families of the Institutionalized Children are not opposed to community-based services. In some ways, I perceive this conclusion to be fairly unremarkable. Indeed, the State's own witnesses seemed to support the notion that a great number of parents would prefer to be able to care for their children at home.

But I am not suggesting that my common-sense impressions are sufficient to satisfy this element of *Olmstead*. The United States presented the expert testimony of Dr. Amy Houtrow on this issue, and her testimony was credible and convincing.[47] She and the other two experts on the

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[47] Dr. Houtrow's testimony is available at DEs 907 and 908. Dr. Houtrow, MD, PhD, MPH, is an expert in the care of children with medical complexity and medical decision-making. An endowed professor of pediatrics and physical medicine and rehabilitation at the University of Pittsburgh

United States' team conducted interviews of numerous parents and caregivers in this case. Their methodology was sound. The experts concluded, and Dr. Houtrow testified, that the parents and guardians of the Institutionalized Children do not oppose community placement.

1. *Applicable Law: "Non-Opposed" Is Not Interpreted by Reference to Barriers*

The Parties do not agree on what "non-opposition" means under *Olmstead*. The United States contends that a parent should be considered "non-opposed" if community placement is their preference, regardless of whether they have the present ability to care for the child at home. The State contends that this interpretation would render the non-opposition element meaningless, in that no parent would oppose bringing their children home under hypothetical, pie-in-the-sky conditions. Thus, the State argues that it has proved that many parents simply cannot bring their children home, due to certain real-world conditions, and therefore it would be erroneous to deem them to be "non-opposed" to community placement. In an effort to prove its point, the State introduced the testimony of several parents and caregivers who chose institutionalization; it cross-examined the parents called by the United States; and it submitted numerous Freedom of Choice Forms, in which parents whom the United States categorized as "non-opposed" opted to have their children continue residing in nursing facilities. According to the State, this undermines the United States' experts' conclusions.

I disagree with the State's proposed interpretation of the non-opposition element. The relevant question is whether service recipients with disabilities would choose community-based services if they were actually available and accessible – *see, e.g.*, *Kenneth R. v. Hassan*, 293 F.R.D. 254, 270 n.6 (D.N.H. 2013) (emphasis in original) ("[T]he *meaningful* exercise of a preference will be possible only if an adequate array of community services are available…."), *DAI II*, 653 F.

School of Medicine, Dr. Houtrow is a pediatric rehabilitation medicine physician who has been in practice for nearly twenty years. (DE 907 at 140). She holds a Masters in Public Health (focusing on Health Policy and Management) and a PhD in Medical Sociology, in addition to her medical degree. (*Id.* at 136). Dr. Houtrow has published more than 100 manuscripts on health services, including papers that focus specifically on children with medical complexity. (*Id.* at 147-48). She has extensive training and experience in both qualitative and quantitative research methods, including designing and implementing studies utilizing semi-structured interviews (qualitative) and designing and implementing surveys and randomized control trials (quantitative). (*Id.* at 147-51). She serves on the Executive Committee of the American Academy of Pediatrics' Section on Home Care and was previously a member of the Academy's Executive Committee of the Council on Children with Disabilities. (*Id.* at 156-57). In her medical practice at the University of Pittsburgh Medical Center Children's Hospital of Pittsburgh, Dr. Houtrow has interviewed thousands of families of children with disabilities and medical complexity, and her daily clinical work includes eliciting information from families regarding their goals, hopes, and concerns for their children's recovery and medical care. (*Id.* at 140-41). She has led hundreds of care conferences and participated in hundreds more. As part of her clinical practice, she also created and oversaw a program that provided Care Coordination, goal-setting, education, and empowerment services for families of approximately 160 technology dependent children for five years; and was the medical director of an inpatient pediatric rehabilitation unit. In all these roles, Dr. Houtrow collaborated with each child's family and interdisciplinary team of providers to develop care goals, including goals regarding the settings to which children would discharge.

Supp. 2d at 263 (people reporting "a preference to move out of their adult home is merely 'a floor' with regard to who would truly be willing to move if given" information and support in making a "true choice"), *Messier v. Southbury Training Sch*., 562 F. Supp. 2d 294, 332-34, 339-42 (D. Conn. 2008) (finding plaintiffs not opposed to community services where guardians expressed "interest" in, or would consider, community placement) – not whether persons with disabilities (or, in this case, their parents or guardians) would accept discharge to the community today, with inadequate access to community-based services. If the latter were the case, it would defeat the purpose of the integration mandate.

Contrary to the State's suggestion, I think that a parent can appropriately be characterized as "non-opposed" even if they are not presently and actively seeking immediate discharge of their children from nursing facilities. Again, most parents want their children at home, but they face barriers, many of which can be overcome if the State did a better job at providing necessary services and support.

Alternatively, even if I were to accept the State's interpretation, it could only prevail on this element of *Olmstead* if the evidence demonstrated that most of the families were in fact ill-equipped and/or unready to care for their kids at home, in that enough of them had personal reasons (*outside* the State's failure to provide services) for choosing nursing facility placement so as to render the group as a whole to be "opposed" to community living. To the extent that the State suggests it proved this, as a factual matter, I disagree. I acknowledge that a number of parents testified to being unable to bring their children home due to personal barriers or general "non-readiness" for reasons unrelated to the availability of Medicaid services. But given the evidence as a whole, it is my perception that those instances are outliers. Such atypical cases cannot support a finding that most families' real-world circumstances preclude them from caring for their children at home.

2. Expert Testimony Regarding Caregiver Interviews

Dr. Amy Houtrow was one of the United States' three experts who jointly addressed the question of whether the parents and guardians of the Institutionalized Children oppose or do not oppose community placement for their children.

The three experts used qualitative research methods and their clinical expertise to conduct and analyze interviews of the families of the Institutionalized Children. In academic research, and particularly in the field of health services, "qualitative" methodologies are universally recognized as appropriate, reliable tools to collect and assess human experiences. Qualitative research methods use data collection tools that elicit participants' detailed and nuanced experiences, feelings, and goals. Instead of drawing numerical conclusions, as quantitative methods are meant to do, qualitative methods are used to identify themes. Researchers identify when qualitative data have reached a point of "saturation," meaning that researchers have confidence that they have achieved a robust understanding of participants' experiences, and no new themes are likely to emerge from additional research.

The "semi-structured interview" is one type of qualitative research data collection technique. It involves an interview guide that has enough consistency to ensure that each interview elicits the necessary content, as well as enough flexibility to allow for nuanced adjustment given the variability of the interviewees' experiences. Semi-structured interviews are analyzed to identify themes that occur across interviews, until a point of data saturation is reached.

To determine whether the Institutionalized Children's parents opposed or did not oppose having their children receive their care at home or in other community-based settings, the United States' experts developed a two-part methodology to conduct semi-structured interviews of families of Institutionalized Children. First, they developed an outreach guide for contacting families. They took precautions and utilized certain protocols in order to minimize bias. Second, they composed a semi-structured interview guide that they used to conduct the interviews. In creating the guide, they sought to ensure consistency and reproducibility to gather evidence of opposition or non-opposition. In conducting the interviews, the experts employed a "care conference conversational approach."[48]

Consistent with this approach, the experts ensured that at least two of the three of them participated in each interview, with one physician taking on the role of lead interviewer and the other physician(s) taking notes. Immediately after each interview, the experts conferred and confirmed whether they agreed that the interviewee had expressed non-opposition or opposition to the child's placement at home or in the community. As they went, they sought to develop consensus regarding their determinations of non-opposition and opposition, and they discussed themes regarding the families' views to assess when data saturation had been reached. That occurred at interview number 21, but the experts went on to conduct a total of 45 interviews of parents of Institutionalized Children, which served to further reinforce their thematic findings.[49]

Based on their analysis of the interviews, the experts concluded that the Institutionalized Children's families "overwhelmingly" do not oppose community placement for their children.[50]

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[48] This approach is recognized in the medical field as a tool that is used to elicit medical goals of patients or their caregivers. *See* USA Ex. 4622 at 34 (App. C). Care conferences are meetings between health care providers and patients and, in the case of pediatric patients, the children's families, in which the family's goals for the child's care are elicited and then incorporated into the child's plan of care. An evidence-based body of literature undergirds how physicians approach interactions with families during care conferences.

[49] The themes identified were: (1) "many families [were] actively seeking to bring their children home" from the nursing facilities; (2) some families wanted their children home but felt appropriate home and community-based services were not sufficiently available to make this preference a reality; (3) some families were not opposed to their children transitioning to a community-based setting other than their own homes; and finally (4) one family was opposed to transitioning their two children from a nursing facility, though the experts concluded that that family's unique circumstances were "not reflective of the common experiences of the Institutionalized Children's families." *See* USA Ex. 4622 at 10, 13.

[50] USA Ex. 4622 at 11; USA Ex. 4623 at 43; USA Ex. 4625 at 22. The State characterizes Dr. Houtrow's conclusions as quantitative, and on that basis suggests that Dr. Houtrow's qualitative methodology was a mismatch, and therefore her opinion is invalid. I was not convinced by these arguments. The State's expert witness on this issue was Dr. Shampanier who holds a PhD in "Management Science" and is an expert in consumer behavior, judgement and decision-making, and related research. Her field involves "measuring preferences," and I have no cause to doubt her qualifications or her particular expertise. Dr. Shampanier opined that the United States' experts' use of qualitative methods, rather than quantitative ones, was inappropriate because the United States' experts used them to draw quantitative conclusions. (DE 894 at 87). I do not agree with her

3. Other Evidence of Non-Opposition

Even 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. These sentiments were expressed by witnesses on *both* sides:

Bobby King, the 27-year-old mother of a little girl residing at Sabal Palms, testified on behalf of the State. She said her daughter is at Sabal Palms because "I have no choice, that is where my decision comes from." (DE 910 at 227). Her home is not large enough to accommodate her daughter, so she signs Freedom of Choice forms authorizing the child's continued institutionalization. She testified: "I would like her out of the facility where I can take care of her, that is my ultimate goal." But to make that happen, Ms. King needs assistance and services: "she needs her own room," "extra help," with "extra nurses," "transportation to…go to her doctors," "medical [equipment] stuff…" (*Id.* at 227-28).

Marcelia Dalmous also testified on behalf of the State. She has a nine-year-old son who has resided at Kidz Korner since birth. Ms. Dalmous lives in the Bahamas. She said that perhaps a child's medical condition may warrant their residence in a nursing facility, but a child's family situation should not be the reason. Ms. Dalmous said: "I think a child needs to bond with other family members," and she further said that if she could relocate to Florida, and if she could feel secure in her ability to care for him, she would want her son at home. (DE 910 at 237-39).

Shawna Williams testified for the State also. Her 2-year-old daughter has lived at Kidz Korner since her premature birth and discharge from a prolonged hospital stay thereafter. Although she expressed that she was happy with the care her daughter has been receiving at the facility, she confirmed that her "first choice" was to care for her child at home. She just could not, because she was told there would not be adequate nursing support, and she is single, with three other kids at home. She said that due to "limited resources available . . .there was never a fully open door" to being able to care for her child at home, so Kidz Korner was the answer. (DE 894 at 30).

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premise that the United States' experts drew quantitative conclusions. They did not opine that because 43 of 44 interviewed families do not oppose community-based services for their children, a specific, exceedingly high numerical percentage of all Institutionalized Children's families are non-opposed with a confidence interval of a certain percentage. Rather, they opined that, based on the qualitative data gathered, the Institutionalized Children's families "overwhelmingly" do not oppose community placement. The use of descriptors like "overwhelmingly," "overall," "many," and "most" to describe findings from qualitative data is consistent with principles of both qualitative *and* quantitative research methods. *See, e.g.,* Margarete Sandelowski, *Real Quantitative Researchers Do Not Count: The Use of Numbers in Qualitative Research*, 24 Res. In Nursing & Health 230, 231 (2001). Thus, I find that the United States' experts' non-opposition methodology is a sound application of qualitative research methods. Dr. Shampanier does not have expertise nor familiarity with the research methodologies used by the United States' experts, and I find that her opinions regarding those methodologies is not entitled to weight and do not undermine their conclusions.

Beatrice Soliz testified for the State. Even though she was comfortable with her decision to place her grandchild in a nursing facility, due to the family's unique circumstances, including Ms. Soliz's responsibility for caring for her husband with Parkinson's, she explained that initially, Francisca lived at home. "We didn't want to do it [transition her to Kidz Korner], but we needed the help[]" because Francesca's condition "got really bad" and she "needed total care." (DE 894 at 51).

Beyond these witnesses' accounts, other evidence of parents' general sentiment of non-opposition was presented through the testimony of nursing facility staff from Sabal Palms and Kidz Korner, who meticulously catalogued the present status of each patient. The State's own witness, Brenda Legge from Sable Palms, affirmed that parents would "absolutely" love to have their children home, but that some of them were "scared." (DE 912 at 280-81). She also testified that "[t]he goal is always for the children to be with their families." (*Id.* at 247). Plus, numerous patients at both Sabal Palms and Kidz Korner were either in the discharge planning process (*see, e.g.*, DE 909 at 18-20, Testimony of Michael Rodriguez stating that he and his wife had been preparing a room and buying necessary equipment to bring their daughter home), or they had expressed an interest in transitioning their child home as a goal (*see, e.g.*, D.E. 840, Pretrial Stipulation, Section VI, ¶ 27; D.E. 785-31 at 50-52, 68-70; 111, 496-497). Clearly these families would properly be characterized as "non-opposed."

Still other families have expressed that they would like to transition their children home but cannot due to barriers such as an inability to obtain home nursing in their area.

4. The State's Attempt to Undermine Evidence of Non-Opposition

Aside from offering the testimony of an expert to challenge the United States' experts' methodology, the State also sought to undermine the evidence of non-opposition by arguing that the experts' conclusions regarding families' preferences were factually wrong. The State contends (1) that "a significant number" of parents interviewed signed Freedom of Choice forms indicating that they *do* oppose community placement; and (2) that "a significant number" of parents interviewed testified that they, in fact, oppose community placement.

As to the first point, the State's attempted defensive use of the Freedom of Choice forms is not persuasive given the way these forms are being completed. It is a perfunctory and virtually meaningless exercise. Parents are signing because they think they have no other options. No one is explaining to them what alternatives exist to institutionalization or what services exist to assist them in bringing their children home. As a gauge of a parent's true wishes, the Freedom of Choice forms are only as good as the process by which the State is achieving this purported consent to continued institutional placement. Of course, a parent is going to check the box that says "I choose the nursing facility" if in that moment, they have no medical equipment at home and no assurance that private duty nurses will show up to help them. If they check anything else, they fear their kids' health and safety may be jeopardized. Take Jeffrey Keys, for instance, who testified for the State. He said that it was his understanding that he could care for his daughter at home with PDN, but he is fearful that nursing would be inconsistent, and if no nurse is available, he would have to care for Emily on his own. He feels uncomfortable doing that, therefore he always elects to authorize Emily's continued institutionalization when the FOC form is presented to him.[51] A family's box

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[51] Caden's father, Conlon Amore, reported feeling similarly compelled to select the option for Caden to remain institutionalized. This was a common theme in many of the families' accounts.

check on the Freedom of Choice form does not equate to opposition to community living. I attribute little or no weight to these.

Moreover, I take issue with the idea that a parent who is not "ready" to transition their child home is *opposed* to bringing their child home, even if their unreadiness is due to personal circumstances and not the State's failure to provide adequate services. They may want to if they could, and that means they are non-opposed within the meaning of *Olmstead*.

As to the second point, I recognize that some caregivers testified that they chose a nursing facility placement for their child. This does not diminish or undermine the United States experts' conclusion, which was premised upon a sound methodology, and which sought to discern the *overall* sentiment of the larger group of parents. The State points out that some families of Institutionalized Children testified that they were happy with the care their children were receiving in nursing facilities. This may be so, but it does not diminish the broader and more dominant sentiment of most, which is a desire that their children live at home.

5. Conclusion: The Families are Not Opposed to Community Placement

If a service recipient with disabilities would be open to choosing community based services if such services were available and accessible, then that person is "non-opposed" within the meaning of *Olmstead*. Dr. Houtrow credibly testified that the families of the Institutionalized Children are overwhelmingly not opposed to community-based services. Moreover, the evidence established that many families were actively in the process of getting their children discharged from nursing facilities, and many others wanted to bring their children home but were experiencing barriers to transition, such as inadequate PDN, ineffective Care Coordination, and/or poor discharge planning with respect to training and other issues. Still other families expressed a desire to bring their children home eventually, as an ultimate goal, but were not prepared to do so for a variety of reasons, both personal and due to service gaps. All of this constitutes compelling evidence of non-opposition and supports the United States' experts' conclusion.

C. Reasonable Accommodations

The United States has presented compelling evidence that the State of Florida is limiting access to home and community-based services for institutionalized children with medical complexity and children who are at risk of imminent institutionalization. Florida is required by the Medicaid Act to provide these services, when medically necessary, to all Medicaid-enrolled children. Florida need only ensure access to its existing services to address these failures and give families a meaningful choice as to whether their children will receive services at home or in nursing facilities.

1. Applicable Law

The final element required to demonstrate a violation of the integration mandate is that the State can make reasonable modifications to its service system to accommodate placement in the community. *Olmstead*, 527 U.S. at 587, 607. Public entities must make reasonable modifications when necessary to avoid disability discrimination. 28 C.F.R. § 35.130(b)(7)(i). The United States' *prima facie* burden of identifying a reasonable modification is not a "heavy one." *Henrietta D. v. Bloomberg*, 331 F.3d 261, 280 (2d Cir. 2003) (affirming grant of injunctive relief after bench trial) (citing *Borkowski v. Valley Cent. Sch. Dist.*, 63 F.3d 131, 138 (2d Cir. 1995)). *See also United States v. Mississippi*, No. 3:16-CV-622, 2019 WL 2092569, at *4 (S.D. Miss. May 13, 2019) ("It is enough for the plaintiff to suggest the existence of a plausible accommodation, the costs of which, facially, do not clearly exceed its benefits, and once the plaintiff has done this, she has made out a *prima facie* showing that a reasonable accommodation is available, and the risk of nonpersuasion falls on the defendant.").

2. Expert Testimony of Dr. Bachman

The United States presented evidence of the existence of reasonable accommodations primarily through the testimony of Dr. Bachman. I note that it is necessary to distinguish the proposed accommodations set forth below (which are findings of fact relevant to the third *Olmstead* element), from the remedy, which is an issue appropriately addressed after liability has been established. Florida conflates this distinction. The following evidence was presented of proposed reasonable accommodations in each service area:

a. **Recommendations Relating to Private Duty Nursing**

Dr. Bachman identified what she believed are reasonable accommodations that Florida could make to address the gaps in PDN services, specifically (1) conduct more robust data collection and analysis, (2) investigate what kinds of network adequacy standards would improve access to PDN, and (3) examine reimbursement rates. (DE 909 at 120-22).

i. Data Collection

To properly examine the existing problems with the provision of PDN and other services and to monitor the ongoing provision of such services, Dr. Bachman and Mr. Jessee recommend that Florida could collect both more data and better data. Dr. Bachman recommends that Florida collect data to look at systemic factors that might be influencing why children are not receiving authorized PDN hours, such as how many home health agencies are in each county, how many nurses are employed by the home health agencies, and whether a particular home health agency is able to meet a child's needs. (DE 909 at 114). Mr. Jessee suggests asking for and examining comprehensive care reports that managed care plans already collect to develop a comprehensive understanding of PDN utilization rates. (DE 897 at 45). Mr. Jessee explained that managed health plans already document every care coordinator's interaction with a child's family, every interaction with providers, hours authorized for services, and hours paid for services. (*Id.*). Mr. Jessee also confirmed that Florida has the authority to require such data collection from managed care plans and to conduct studies to identify gaps in the provision of services. (*Id.* at 142-44). Indeed, he confirmed that Florida could collect data relevant to understanding why children with medical complexity are not receiving their authorized PDN hours by sending a single email request. (DE 912 at 46).

ii. Network Adequacy Standards

Dr. Bachman also explained that provider networks are key for ensuring access and is one of the first things she would look at if she were working with Florida. (DE 909 at 120). She recommends that the State try to understand more about the needs of children and how those needs can be met by setting PDN-specific network adequacy standards. (*Id.* at 122). The State could do this via its contracts with the managed care plans by, for example, setting the number of home health agencies in each county based on the number of children who need PDN in that county. (*Id.*). Ann Dalton, the Chief of AHCA's Bureau of Medicaid Policy, confirmed that AHCA includes network adequacy standards in their contracts with the Department of Health; AHCA can also amend its contracts while they are in effect to modify the network adequacy standards, including increasing the minimum number of home health agencies required for each county. (DE 894 at 181).

iii. PDN Reimbursement Rates

Dr. Bachman also recommends that Florida look at the reimbursement rates for PDN, which is typically set by the managed care plan but which the State can influence by setting a minimum reimbursement rate. (DE 909 at 115-16, 124-25). To compare Florida's reimbursement rates with those of other states, she recommends contacting each state's Medicaid program to obtain that data, so that a systematic review of rates could be conducted. (*Id.* at 116). She also explained that some of that data is available publicly but that the reimbursement rates of private managed care plans are proprietary information. (*Id.* at 116-17). Of course, Florida could require, by contract, that the managed care plans provide their reimbursement rates to Florida. *(Id.* at 117). Raising reimbursement rates is one option for Florida to encourage more PDN. (*Id.* at 125). Although Dr. Bachman did not compare Florida's reimbursement rates with those of other states, she examined several single-case agreements that showed the managed care plans were able to entice private duty nurses to take a case based on an increased reimbursement rate. (*Id.* at 125-26). In addition, she explained that based on her experience, she knows that raising reimbursement rates for services improves access to those services. (*Id.* at 127). Although Mr. Jessee did not agree with Dr. Bachman's recommendation that Florida should consider raising reimbursement rates,[52] he agreed that Florida has the authority to do so, including by using a phased approach over time and by establishing stratified reimbursements rates based on acuity (*i.e.*, lower PDN rates for children without medical technology and higher PDN rates for those with ventilators or co-concurring behavioral and mental health needs). (DE 897 at 144-45).[53]

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[52] Mr. Jessee did not agree with Dr. Bachman's recommendation that Florida should consider raising PDN reimbursement rates. (DE 897 at 77-78). He testified that based on his review, Florida's reimbursement rates for PDN are comparable to other states' rates, even "pretty favorably." (*Id.* at 64). However, when pressed on cross examination, his opinion was shown to be contrary to the data, and misleading. Mr. Jessee failed to consider that many states use a modifier to provide a higher rate for PDN where a child requires a tracheostomy or ventilator, for example. As Mr. Jessee recognized and Ms. Dalton confirmed, Florida, however, pays the same PDN rate regardless of the level of patient care, meaning that Florida does not use a modifier. (DE 894 at 186-89). Mr. Jessee used the base rates in his comparison, ignoring the fact that in other states the PDN rate would be increased for the children at issue in this case. (DE 897 at 177). In fact, review of the *actual* fee-for-service PDN rates for this population showed that Florida had one of the lowest hourly rates for PDN at $29.10, whereas South Carolina pays $42.00, Georgia pays $46.76, Texas pays $52.12, Mississippi pays $58.65, and Louisiana pays $67.43. (*Id.* at 171-77, 180) These amounts include modifiers. (DE 897 at 177). Up until that point I found Mr. Jessee to be knowledgeable, engaging, and candid. But I attribute no weight to Mr. Jessee's opinion regarding comparable PDN rates. Florida's PDN reimbursement is not comparable to other states and in fact, given the cost of living in Florida, is remarkably low.

[53] It is apparent that AHCA recognizes that nurse's pay is a problem. Ms. Patton, AHCA's head of the Bureau of Medicaid Policy confirmed that AHCA submitted a budget request for FY 2022-23 asking for a 4% provider rate increase to account for the need to recruit and retain PDN

b. Recommendations Relating to Care Coordination

Dr. Bachman recommends that the State require managed care plans to collect certain Care Coordination information in a format that is capable of systematic analysis, which could serve as an important tool for monitoring Care Coordination services for children with medical complexity. (DE 909 at 156). In terms of holding managed care plans accountable for Care Coordination, Dr. Bachman recommends that Florida analyze its current Care Coordination standards and determine whether the standards are effective. (*Id.* at 156-57). Suggested guidelines include those recommended by the Catalyst Center and the Maternal and Child Health Bureau.[54] (*Id.* at 158). Mr. Jessee confirmed that Florida has the authority to require its managed care plans to use evidence-based tools for Care Coordination and tracking. (DE 897 at 149).

c. Recommendations Relating to iBudget Waiver

To address the gaps in Florida's iBudget waiver program, Dr. Bachman suggests designating some of the existing slots in the program for children with medical complexity. (DE 909 at 148). Also, given the rating system used for the waiting list—Category 1 to Category 7, with children falling under Category 7—Dr. Bachman recommends determining whether any of the children in Category 7 might also qualify for a higher tier, allowing them to essentially move up on the waiting list. (*Id.* at 149). Mr. Jessee confirmed that Florida has the authority to implement these recommendations. (DE 897 at 148-49). Moreover, over the past several years, Florida has been requesting and receiving approximately 1500 additional spots each year. Some of those spots could also be designated for children with medical complexity.

d. Recommendations Relating to Medical Foster Care

The State should specifically recruit medical foster care parents for those children residing in nursing facilities while in state custody. Dr. Bachman suggests evaluating the reimbursement rates that Medicaid pays to medical foster parents and considering whether those rates need to be adjusted. (DE 909 at 137). Ms. Dalton confirmed that Florida has a fee-for-service schedule for medical foster care services and that it can raise the rates, as it recently did to reflect Florida's new minimum wage for direct service workers. (DE 894 at 189). Relatedly, Dr. Bachman explained that Florida should adopt a quality assurance mechanism for the Medical Foster Program, perhaps similar to Florida's existing quality assurance process that is currently on hold, although it may have resumed. (DE 909 at 137-39). Mr. Jessee said this quality assurance process was on hiatus but is no longer on hold. (DE 897 at 127). Mr. Jessee confirmed that Florida had the authority to do all of these proposed recommendations. (DE 897 at 126-27; DE 912 at 56-57).

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providers to provide "skilled nursing care to children in Medicaid whose medical condition requires care to be delivered in their home or community." (DE 894 at 198-99; USA Ex. 4509). The budget request further stated: "A rate increase could help expand the network of providers that are willing to provide PDN and will help providers recruit and retain sufficient nurses to meet the needs of children." (DE 894 at 199; USA Ex. 4509).

[54] The Catalyst Center was started by Dr. Bachman and is based at Boston University's School of Social Work. *See* https://ciswh.org/project/the-catalyst-center/. The Maternal and Child Health Bureau is a bureau within the Health Resources and Services Administration, an agency of the U.S. Department of Health and Human Services. *See* https://mchb.hrsa.gov/.

3. Monitoring, Oversight and Accountability Mechanisms

In addition to the four key Medicaid services for children with medical complexity, Dr. Bachman and other experts saw an opportunity to close the gaps in the provision of services by improved monitoring of the managed care plans and through the utilization of existing accountability mechanisms. Dr. Bachman observed that "Florida's Medicaid program is . . . an extremely complicated system with multiple state agencies involved and multiple relationships." (DE 909 at 160). "[T]here are gaps in services . . . because there are gaps in effective accountability for who is responsible for what." (*Id.* at 161).

To that end, Dr. Bachman recommends that Florida ensure it is monitoring how the managed care plans are providing services for children with medical complexity and holding its managed care plans accountable. (*Id.*). In terms of monitoring, Dr. Bachman explained that states are required to oversee the managed care plans' provision of services, including by using an External Quality Review Organization ("EQRO"). (*Id.* at 159-60). Florida is required to contract with an EQRO and to plan how the EQRO will evaluate the quality of its managed care plans. (*Id.* at 160). Dr. Bachman opined that Florida could do more to monitor the functionality of its managed care plans by requiring the EQRO to include performance measures specific to understanding the access issues faced by children with medical complexity, given that the EQRO's most recent report does not include much relevant to those children. (*Id.* at 165-66). Mr. Jessee agreed that Florida has the authority to require the EQRO to design and conduct a specialized review of PDN authorization and utilization for children with medical complexity; it could also consult other professionals to develop other tools to address service gaps. (DE 897 at 56-59, 149-151).

In terms of accountability, Florida's contracts with its Medicaid managed care plans provide accountability mechanisms – corrective action plans, liquidated damages, and sanctions – that would allow it to penalize managed care plans for failing to provide medically necessary services to children under the age 21. (DE 909 at 163-64). Dr. Bachman explained that utilizing these mechanisms, the hope is that the managed care plans "will stop the poor performance." (*Id.* at 165). In other words, Florida should ensure that AHCA holds the managed care plans accountable for what they are supposed to be doing, pursuant to their contracts. (*Id.* at 166). Mr. Jessee and Ms. Dalton confirmed that Florida could utilize the contractual accountability mechanisms, including by imposing liquidated damages in the amount of $2,500 per occurrence for failing to provide medically necessary services, which Mr. Jessee said Florida has never done (at least since 2018). (DE 912 at 52; DE 894 at 182-83).

Ms. Dalton testified that she was not aware of any formal analysis undertaken by Florida to assess whether children enrolled in Medicaid are receiving all of their authorized services, including whether there are any discrepancies based on whether children are enrolled in fee-for-service programs versus managed care plans. (DE 894 at 185). Ms. Dalton also confirmed in her testimony that the current contract cycle for managed care plans will end in 2024 and that new contracts could include new reporting requirements and new performance standards. (*Id.* at 197-98).

Florida's contracts with its managed care plans and fee-for-service providers cover many, if not all, of the topics discussed, such as network adequacy networks, Care Coordinator caseloads, reporting requirements, and performance standards. And to the extent that those standards or requirements are insufficient, the State has the ability to change them, even mid-contract.

4. Conclusion: Reasonable Accommodations Could be Made

Based upon the foregoing, I find that the United States has suggested the existence of plausible accommodations.

Proposed modifications that expand existing services are a plausible reasonable accommodation, particularly when the modifications align with the jurisdiction's own stated plans and obligations. *See, e.g.*, *Henrietta D.*, 331 F.3d at 280-81 (upholding as a reasonable modification an order requiring agency to follow existing law and procedures); *United States v. Mississippi*, 400 F. Supp. 3d 546, 576 (S.D. Miss. 2019) (finding provision of community-based services reasonable where United States showed that the state "already has the framework for providing the[] services and can more fully utilize and expand that framework to make the services truly accessible."); *DAI I*, 598 F. Supp. 2d at 335-36 (emphasis in original) ("Where individuals with disabilities seek to receive services in a more integrated setting—and the state *already provides* services to others with disabilities in that setting—assessing and moving the particular plaintiffs to that setting, in and of itself, is not a 'fundamental alteration.'"); *Messier*, 562 F. Supp. 2d at 344-45 (plaintiffs' requested service expansion, which was consistent with defendants' publicly stated plans, was reasonable); *cf. Haddad*, 784 F. Supp. 2d at 1330-31 (providing a service already in state's service system to additional individuals is not a fundamental alteration).

The United States has identified modifications the State can make to its existing services and program administration, as set forth above. These modifications, which 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, are both sufficient to meet the *prima facie* burden of articulating a plausible modification, and they are reasonable. *See, e.g.*, *Mississippi*, 400 F. Supp. 3d at 576; *DAI I*, 598 F. Supp. 2d at 335-36; *cf. Haddad*, 784 F. Supp. 2d at 1304-05.

The modifications also comport with Florida's own standards and obligations. For example, the State requires its managed care plans to ensure provision of all services deemed medically necessary, including PDN, and requires plans to use financial incentives where necessary to meet this obligation. This is consistent with the State's separate and independent legal obligation under federal Medicaid law to provide all medically necessary services to Medicaid-enrolled children. *See* 42 U.S.C. §§ 1396a(a)(43), 1396d(a), 1396d(r)(5). Modifications that align with the jurisdiction's own stated plans and obligations are reasonable. *See, e.g.*, *Henrietta D.*, 331 F.3d at 280-81; *Messier*, 562 F. Supp. 2d at 344-45.

Moreover, because the State already must make medically necessary services accessible to all Medicaid-enrolled children with medical complexity, 42 U.S.C. §§ 1396a(a)(43), 1396d(a), 1396d(r)(5), meeting this obligation is inherently reasonable.

D. <u>Florida's "Substantial Modification" Defense</u>

Once the plaintiff has met the prima facie burden of proposing reasonable accommodations, the burden shifts to the defendant to demonstrate the fundamental alteration defense. 28 C.F.R. § 35.130(b)(7)(i) ("A public entity shall make reasonable modifications . . . unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity."); *see, e.g.*, *Brown v. District of Columbia*, 928 F.3d 1070, 1077-78 (D.C. Cir. 2019) (collecting cases).

At summary judgment, the State prevailed on its substantial modification defense with respect to requiring the State to seek additional iBudget waivers and elimination of the parental rights requirement for Medical Foster Care. None of the remainder of the federal government's recommendations (or the remedies contained in the injunction, although that is a separate issue) fundamentally alter the State's programs.

One aspect of the State's argument, as I understand it, is that with respect to this defense, the State could not precisely formulate a theory, or plan an evidentiary rebuttal, because it did not know with sufficient specificity what the United States would be seeking in terms of a remedy. But this conflates the "reasonable accommodations" element of *Olmstead* with the Court's subsequent, post-liability determination of injunctive relief. The Parties briefed this issue post-trial. I agree with the United States that its pretrial disclosures regarding recommended accommodations were detailed enough to put the State on notice and enable it to plan its defense. That the ultimate remedial language is more detailed does not mean that the State could not prepare and present evidence that the accommodations would result in a "substantial modification."

Arguably the most significant component of the United States' proposed accommodations (and the most important part of the remedy being ordered here) is the provision of PDN services to families. The government proposed a percentage increase in access to PDN as a reasonable modification. It sought 90% of all PDN hours as a reasonable accommodation. (DE 914 at 2). I am ordering that the State meet a 90% threshold for PDN delivery. As to the existing PDN deficit, the State undoubtedly knew this was a massive problem and a central issue in the case from the beginning. It cannot now claim surprise. Had it chosen to, the State could have prepared evidence to attempt to persuade me that to require it to start providing all (or a high percentage of) medically necessary PDN would result in a substantial modification of its programs. It chose not to present such evidence, and therefore the State has suffered no prejudice to its ability to put on a defense. And moreover, even if the State *had* known that the remedy would set the PDN threshold at 90%, and even had it been given all the conceivable time it needed to prepare, the State cannot credibly advance the position that providing this level of PDN would be a substantial modification of its programs. The remedy being ordered is similar to that of which AHCA and the Florida Legislature previously required, as will be explained in further detail below. Furthermore, there can certainly be no "substantial modification" of a program when that program is already obligated to provide 100% of the medically necessary service at issue.

In sum, the State has had ample opportunity to present a substantial modification defense pertaining to PDN services or any other aspect of the proposed reasonable accommodations put forward by the United States. It chose not to do so, and it has suffered no prejudice.

X. THE REMEDY

Acknowledging that the "United States proved that several families have endured tragic circumstances and face very real hardships," the State argues that "[s]tories of heartbreak can spur legislative action, but they cannot invoke the jurisdiction of this Court." (DE 925 at 27). The State expresses fear of "a broad, federal takeover and long-term micromanagement of entire services in the Florida Medicaid program." (*Id.* at 26). These fears are both misplaced and overblown.

I am obligated to enforce the ADA, as passed by Congress and interpreted by the United States Supreme Court. Because the State's administration of its Medicaid program discriminates against children with medical complexity, the remedy is to make reasonable modifications to

Florida's policies, practices, or procedures. *Olmstead*, 527 U.S. at 592. The injunction is focused on remedying the failures shown at trial and what the State is required to do is well within its capabilities. The population of children affected is limited. The specific findings and remedies have been identified by not only the witnesses called by the United States but also those called by the State.[55]

The remedies do not contemplate or require a "takeover" of Florida's Medicaid program. As I advised the parties at the close of evidence, mindful of federalism concerns, I am wary of federal injunctions that are intrusive and last too long. The remedy ordered is specific and tailored to make essential changes quickly.

While I urge the State to consider the well-reasoned recommendations of Dr. Bachman and the federal government, the injunction I am entering is much more limited.[56] The State is only ordered to do three things: (1) Require the managed care plans to ensure the provision of all covered and authorized PDN and develop methods to measure provider performance, including real time reporting of PDN provider issues; (2) Inform and facilitate the transition of children from nursing facilities; and (3) Improve the existing Care Coordination system to strengthen accountability and eliminate silos of care.

A monitor shall be appointed for a limited period to assist the parties and the Court in ensuring compliance with the injunction. And I encourage the State to increase enforcement of its contracts with the managed care organizations, including adding performance standards where appropriate.

The State had ample opportunity to address the United States' proposed injunction, both in a 35-page responsive brief, a sur-reply, and in closing argument. The injunction necessarily flows from the evidence, is narrowly tailored to the scope of the violation proven at trial, describes the

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[55] The State contends that the United States has not shown a sufficiently widespread problem to warrant systemic relief. I disagree. I find that the ADA violation is widespread, and thus systemwide injunctive relief is appropriate. *See Lewis v. Casey*, 518 U.S. 343, 359 (1996). Most children with medical complexity (1,800 out of 1,956 children) received less than the PDN hours authorized by the managed care plans, with children receiving 70-80% of their authorized hours on average. There are 500-800 children with medical complexity on the iBudget waiver list, including 19 in nursing facilities. There are at least seven children in nursing facilities awaiting placement with a Medical Foster parent, as well as 30 children awaiting placement at the time of trial. There was ample evidence of widespread inefficacy in Care Coordination in providing information to parents about alternatives to institutionalization, discharge planning, and needed services.

[56] Earlier in the case I determined that requiring the State to request additional iBudget waivers and to allow Medical Foster Care where parental rights remain intact would constitute fundamental alterations in the State's programs and therefore are foreclosed by *Olmstead*. While (as Dr. Bachman testified) there are some remaining measures that the State could take to improve the waiver process and medical foster care recruitment, I am focusing the injunction on what I perceive to be the most significant priorities.

acts required in reasonable detail, and provides flexibility in the manner in which the State achieves compliance.[57]

A. <u>**The Managed Care Plans Must be Required to Ensure the Provision of All Covered and Authorized PDN and Develop Methods to Measure and Enforce Provider Performance, Including Real Time Reporting of PDN Provider Issues.**</u>

The relief I am ordering builds on an initiative of the Florida Legislature and includes steps already undertaken by AHCA and the managed care organizations.

In 2020, the Florida Legislature enacted Fla. Stat. § 409.968, which directed AHCA to withhold and set aside a portion of the managed care rates to implement a home health performance incentive program. The legislation required AHCA to "direct Medicaid managed care plans to submit to the agency proposals to ensure *all* covered and authorized home health services are provided to recipients, methods for measuring provider compliance, and mechanisms for documenting compliance to the agency." (emphasis added). 409.968 Managed care plan payments, Title XXX, ch. 409, § 968 (repealed 2021). The legislation also stated: "The plans must implement a method for families and caregivers to report provider failures to provide services in real time."[58] *Id.* AHCA was permitted to disburse the withheld portion only if it documented in writing that the plans ensured that all covered and authorized home health services were provided. By its terms, Fla. Stat. § 409.968 expired July 1, 2021.

Pursuant to this legislative mandate, AHCA issued a series of Statewide Medicaid Managed Care (SMMC) Policy transmittals:[59] 2020-10 (February 24, 2020); 2020-38 (June 26,

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[57] The State also argues that "[i]f Title II of the ADA authorizes the extraordinary remedies outlined in the injunction, then, in this application, it exceeds Congress's constitutional authority and is unenforceable." (Post-Trial Brief Regarding Remedies, DE 925 at 23). Much of this argument is mooted out by the fact that, as I explained, the injunction is more limited than what the United States proposed. (*Supra* note 55). And in any event, the State's argument is simply a reframing of the same two points it has made several times over: (1) the scope of the injunction is too broad and/or (2) the remedy is not a "reasonable modification." I have rejected both elsewhere in this Order. (*See* Parts IX.C, X.). To the extent the State is actually arguing that Title II is unconstitutional as applied in the context of institutionalized children, I find that to be plainly wrong. That is because in *Tennessee v. Lane*, 541 U.S. 509 (2004) the U.S. Supreme Court recognized that Congress enacted Title II "against a backdrop of pervasive unequal treatment in the administration of state services," as reflected in the Court's own opinions identifying "unconstitutional treatment of disabled persons by state agencies in a variety of settings, including unjustified commitment . . . . " 541 U.S. at 510, 524-25 (2004); *see also id.* at 535 (Souter, J., concurring) (noting the judiciary's past endorsement of discrimination against disabled children as another justification for Congress's action under Section 5 of the Fourteenth Amendment).

[58] The full text of Florida Statute § 409.968 "Managed care plan payments.—" (2020) is available at https://www.flsenate.gov/laws/statutes/2020/409.968.

[59] For a complete archive of the 2018-2021 AHCA policy transmittals, visit https://ahca.myflorida.com/medicaid/statewide-medicaid-managed-care/plan-communications-prior-to-2022/agency-communications-to-smmc-plans-2018-2021-archive. Visit

2020); 2020-42 (July 30, 2020); 2020-57 (Nov. 5, 2020); 2020-61 (Nov. 17, 2020); 2021-08 (March 4, 2021); 2021-39 (Dec. 20, 2021); and 2022-03 (March 21, 2022). Through these policy transmittals, AHCA developed the project focusing on private duty nursing. In Policy Transmittals 2020-38 and 2020-42, AHCA requested baseline information concerning the coverage percentage of Private Duty Nursing for January 1, 2019 through December 31, 2019 (2020-38) and then October 1, 2019 through March 31, 2020 (2020-42).

Then in Policy Transmittal 2020-57, AHCA described implementation:

> The managed care plan must submit a proposal that ensures the provision of all covered and authorized PDN and the development of methods to measure provider compliance.
>
> At a minimum, the proposal must address the following components:
>
> - The description of the managed care plan's PDN monitoring strategy, including all methods the managed care plan will utilize to ensure the provisions of authorized PDN services. If financial rewards are a component of the PDN monitoring strategy, the managed care plan must also address financial inducements for high-performing PDN home health agencies.
>
> - Methods for measuring provider compliance with the provision of PDN services. The PDN monitoring strategy must document how the managed care plan proposes to track this information internally and the PDN performance indicators used to determine compliance.[60]

Policy Transmittal 2027-57 indicated that AHCA had worked with its contracted actuaries to develop a withhold and disbursement methodology for the PDN incentive payment. Essentially, the managed care plans could earn back 100% of the amount of their withhold by providing 85% of the authorized PDN. To be eligible to receive any of the amounts withheld, a health plan had to achieve a minimum threshold of 60%. For health plans with a ratio at or above 60% but lower than 85%, the amount disbursed would be the actual percentage divided by 85% (the cap to receive 100% of the withhold).

The Policy transmittal included the following example:

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https://ahca.myflorida.com/medicaid/statewide-medicaid-managed-care/agency-communications-to-smmc-plans-fy2022-23 for the 2022-2023 policy transmittals.

[60] BETH KIDDER, AGENCY FOR HEALTH CARE ADMINISTRATION (AHCA), *Statewide Medicaid Managed Care (SMMC) Policy Transmittal: 2020-57*, at 2 (November 5, 2020), available at https://ahca.myflorida.com/content/download/8065/file/PT_2020-57_ImplementationofthePDNIncentivePaymentandAdHocQuarterlyPDNReport_11.05.2020_.pdf.

Total authorized PDN hours	1,000
Total PDN hours provided	700
Percentage (700/1000)	70%
Health Plan PDN percentage	70%
% of withhold earned (70% / 85%)	82.4%

For this example, the health plan would receive 82.4% of the amount withheld.

In Policy Transmittal 2020-61, AHCA turned its attention to the real-time reporting requirement. AHCA also noted that "[a]t this time, the Agency has limited implementation of the home health performance incentive program to private duty nursing (PDN) services."[61] The purpose of the Policy Transmittal 2020-61 was "to inform the managed care plan of the legislative mandate to implement a method for families and caregivers to report failures to provide services in real time and to issue an ad hoc request for documentation of how the managed care plan proposes to meet this legislative mandate for real time reporting of PDN provider failures."[62]

The policy directive required each managed care plan to "clearly illustrate how enrollees, as well as the enrollees' families and caregivers will report PDN provider issues to the managed care plan on a real time basis."[63] At a minimum, the managed care plans documentation was required to include:

- Details of the process for real time reporting of PDN provider issues;
- How the managed care plan will ensure the provision of all covered and authorized
- PDN services to its enrollees;
- How the managed care plan will provide methods for measuring PDN provider compliance;
- How the managed care plan will notify and educate PDN providers prior to implementations of the real time provider issue reporting;
- How the managed care plan will notify enrollees, families and caregivers of the real time PDN provider issue reporting; and

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[61] BETH KIDDER, AGENCY FOR HEALTH CARE ADMINISTRATION (AHCA), *Statewide Medicaid Managed Care (SMMC) Policy Transmittal: 2020-61*, at 1 (November 17, 2020), available at https://ahca.myflorida.com/content/download/8071/file/PT_2020-61_AdHocReq-for-HomeHealthRealTimeReportingRequirements_11.17.2020.pdf.

[62] *Id.*

[63] *Id.*

- Details of how the managed care plan will resolve PDN provider issues reported through this real time process.[64]

I find this legislation and these policy pronouncements significant for several reasons: (1) the Florida Legislature expressly recognized the need to improve the provision of PDN and attempted to take steps to address it; (2) AHCA confirms the necessity of providing all covered and authorized PDN; (3) the managed care plans have developed and proposed to AHCA methods for ensuring the provision of all authorized PDN, including methods for measuring, tracking, and monitoring provider compliance; and (4) methods for real-time reporting of failures to provide PDN exist and can be implemented.[65]

The injunction that I am entering is intended to continue, build upon, and improve these efforts.

I am not requiring any withholding of funds from the managed care organizations although the state may choose to utilize that tool. Additionally, during trial the State's lawyers argued that the ad hoc reports previously required by AHCA overstated the PDN shortfall because they did not account for factors that could result in less than full PDN utilization, such as declination of services by a parent or hospitalization of a child. The injunction addresses that problem.

Federal Medicaid laws require the State to provide all medically necessary services to these children, which includes authorized PDN. 42 U.S.C. §§ 1396a(a)(43), 1396d(a), 1396d(r)(5). The State's own contracts require 100% provision of PDN, as did the AHCA policy transmittals referenced above. However, to comply with the injunction, the State must only ensure that every PDN child obtain a PDN ratio of 0.9, calculated as follows: (PDN hours delivered) ÷ (PDN authorized hours – PDN hours declined – PDN hours not delivered while the child was hospitalized). Essentially, this is a 90% PDN utilization rate.

I recognize that for a specific child with medical complexity, 90% may not be enough, especially since many of these children require 24-hour care. Nevertheless, I find that a 90% PDN utilization rate 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. The injunction also provides the State great flexibility in achieving that rate, including by requiring that managed care plans raise PDN reimbursement rates, ensuring that the managed care plans comply with network adequacy standards, or utilizing any other tool at its disposal. Nothing in my injunction requires Florida to seek appropriations to achieve this goal.

During the trial, both Dr. Bachman and the State's expert Mr. Jessee agreed that the data collected by the State, both the ad hoc reports and the monthly enhanced Care Coordination reports, were not capable of systemic analysis. Therefore, the injunction requires the State to collect data, alongside enrollee information, showing (i) authorized PDN hours, (ii) any PDN hours declined by the parent/guardian or not required by reason of hospitalization, (iii) PDN hours

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[64] *Id.* at 1-2.

[65] When the incentive program ended, AHCA chose not to continue the ad hoc or real time reporting requirements. During the year funds were withheld, the CMS plan operated by Sunshine Health delivered 73 percent of authorized hours to its approximately 1400 members.

provided, and (iv) if not provided, an explanation for the non-compliance. A parent's reluctance to change a nursing provider is not an acceptable explanation for a lack of compliance by a provider. In addition, the reimbursement rate paid to the child's PDN provider should be collected. Further, the State must collect data on the availability of nurses providing pediatric PDN in Florida. One way to collect this data may be through improving the existing monthly Care Coordination reports to collect PDN information that is capable of systematic analysis.

I recognize the legislature may also be requiring similar information such as the requirements of the Direct Care Workforce Survey mandated by Fla. Stat. § 408.822. It is not my intention to force duplication of data collection. This injunction will be modified to eliminate any redundancy upon notification to the monitor.

Because of the importance of PDN to the child and the fact that a lack of PDN can prove fatal, any failure to provide PDN should be immediately reported. The managed care plan must implement a method for families and caregivers to report provider failures to provide services in real time. In addition, Care Coordinators should directly report any failure to provide authorized and requested PDN hours to their supervisor, with a copy to a designated state agency and the monitor.

B. Nursing Facility Admissions, Transition Planning, and Discharge.

Throughout the trial, there was substantial confusion about the admission, transition planning, and discharge policies at the nursing facilities. Some parents testified they did not know of any option available other than placing their child at a nursing facility, particularly where a child was admitted directly from a hospital. The discharge policies of the nursing facilities vary, and there was confusion even among personnel at a facility about the actual requirements. There was confusing testimony about whether two parents, a parent and another relative, or a parent and a Private Duty Nurse would suffice before a child could be sent home. Some parents thought a private room for their child was required. Parents were often discouraged by the nursing facility personnel's warnings that PDN would be sporadic and often unavailable. Freedom of choice forms were perfunctorily signed because parents felt that if they didn't sign, their children would be denied care. There was confusion about whether a "formal request" was required by a parent to initiate discharge planning. Training requirements were difficult to understand and often applied differently. The injunction contains the following requirements to address this confusion.

1. *Freedom of Choice Form*

The State requires that parents or guardians of children in nursing facilities complete and sign an AHCA-approved freedom of choice form. Indeed, the Sunshine Health contract requires that a freedom of choice form be signed within 7 business days of instituting nursing facility services and every 6 months thereafter while the child resides in a nursing facility.[66] The injunction requires, consistent with the non-opposition element of *Olmstead*, revision of the freedom of

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[66] The contract requires that Sunshine Health ensure that a freedom of choice form is signed "[w]ithin seven business days of instituting nursing facility services and prior to authorizing such services" as well as "[a]t the bi-annual [multi-disciplinary team] meeting every six months thereafter[.]" (DE 965-1 at 96 (USA Ex. 3240)).

choice form to clarify whether a parent or guardian opposes transition of the child to a home or community setting.

The current freedom of choice form has one area to make a choice:

> 2. My choice is indicated in the checked box.
> ☐ I want to receive services in the community.
> ☐ I want to live in a nursing facility (if assessed need exists).

I suggest revising the form for children with medical complexity to the following:

> For children living in a nursing facility:
>
> 2. My choice is indicated in the checked box.
> ☐ **Right now**, I want my child to come home or move to a community setting.
> ☐ **Right now**, I want my child to stay in the nursing facility.
> 3. My choice is indicated in the checked box.
> ☐ I do not oppose my child living at home or in a community setting **in the future**.
> ☐ I oppose my child living at home or in a community setting **in the future**.
>
> For children living at home or in a community setting.
>
> 2. My choice is indicated in the checked box.
> ☐ **Right now**, I want my child to move to a nursing facility.
> ☐ **Right now**, I want my child to stay home or in a community setting.
> 3. My choice is indicated in the checked box.
> ☐ I do not oppose my child living at home or in a community setting **in the future**.
> ☐ I oppose my child living at home or in a community setting **in the future**.

If a parent does not oppose their child living at home or in the community, the State shall prepare a specific transition plan for the child. To the extent the parent expresses confusion about the form, that should trigger further conversations to ensure that the parent is making an informed decision after complete information about the settings available for care, as well as the services available in those settings. While I have proposed suggested revisions to the freedom of choice form, I defer to the State to craft the precise language that addresses my concerns. The main goal of my proposal is to increase the flow of information from the State (via Care Coordinators, CMATs, or whomever) to the parents and guardians with respect to their decision to care for their children in a nursing facility or in a home or community setting. Only with complete and accurate information can parents exercise their choice for where their child's care is provided.

2. Transparent and Specific Discharge Criteria for Nursing Facilities and Transition Planning.

Similarly, in light of the evidence concerning the confusion surrounding how a child can be discharged from a nursing facility, the State must take an active role in ensuring that parents and guardians are informed of the specific discharge criteria for children in nursing facilities. In addition, as already required by contract and regulation,[67] the transition planning process must be regularly conducted. Given that the evidence indicates that discharge planning has not been conducted with consistent clarity and adequacy, I will require that it be done immediately for the children currently living in nursing facilities, with a written transition plan memorializing the specific steps that must be taken to transition the child to a home or community setting. The transition plan should also be updated with regularity, at least every 3 months, with the goal of getting children out of nursing facilities if the parents or guardians desire that. The injunction provides specific steps that are consistent with the way that transition of care is supposed to work, according to the contracts and regulations, including the establishment of a training curriculum for Care Coordinators who serve children in nursing facilities and those who receive PDN. In addition, the State shall require its EQRO to assess and report on the State's performance with respect to providing transition planning for every child living in a nursing facility.

3. Clear Lines of Authority Between Care Coordinator Provided by the Managed Care Plan and the Coordinator at Any Nursing Facility.

The managed care plans are required to provide Care Coordination. The nursing facilities are also required to provide certain duties that fall under the realm of Care Coordination, such as providing a post-discharge plan. Fla. Admin. Code. R 59A-4.1295 (2016). Siloed Care Coordination systems can weaken accountability when services are not provided or when communication is lacking. Given the evidence of the gaps and families' confusion surrounding Care Coordination, the State must develop clear lines of authority between the managed care plan Care Coordinator and personnel at the nursing facilities.

C. Improve the Existing Care Coordinator System to Strengthen Accountability and Eliminate Silos of Care by Service Providers.

The problems with Care Coordination were a consistent thread throughout all of the families' testimony as well as the Care Coordinators' testimony. I found that the coordinators genuinely wanted to help the children receive their authorized care but that they faced challenges, particularly in terms of being limited in what they could do to effect change in the children's care. The most glaring problem involved PDN, where they were limited to simply going down the list

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[67] Fla. Admin. Code. R 59A-4.1295, "Additional Standards for Homes that Admit Children 0 through 20 Years of Age," requires, *inter alia*, that "[t]he facility must, upon admission and quarterly, conduct and include in the resident's plan of care a comprehensive assessment of the resident's functional capacity and a post-discharge plan of care that includes plans, actions and goals to transition the child to a home and community-based, non-institutional setting." Fla. Admin. Code. R 59A-4.1295(3)(c)(5) (2016). The Sunshine Health contract has requirements for "Transition of Care," including, *inter alia*, discharge planning and post-discharge care, collaboration with the institution to implement the discharge plan in the enrollee's home, and the facilitation of communication with community service providers. (DE 965-1 at 97).

of the nursing providers and making telephone calls hoping to obtain coverage. Care Coordinators need to be able to escalate the issue within the managed care organization and the State. The injunction requires them to do so.

Additionally, the State must establish a training curriculum for Care Coordinators which emphasizes that unless a parent or guardian opposes it, every child with complex medical needs is capable of living at home or in a community setting. Care Coordination should be family centered and the State must establish a system where parent(s)/guardian(s) may submit complaints about Care Coordination to a designated state agency.

D. Enforce Contracts with Managed Care Plans, Including Adding Performance Standards, Where Appropriate.

One of the most perplexing aspects of this case is the apparent unwillingness of the State to enforce its contracts. The State has contracted with managed care organizations to establish complete medical provider networks to service the needs of children with medical complexity. Part of the required network is to provide home health care to eligible members in a clinically appropriate and timely manner. The managed care organizations have contracted to deliver, not endeavored to deliver, medical treatment to their members.

Most of these children and their parents are members of Sunshine Health, a subsidiary of Centene Corporation, which represents itself as the largest provider of Medicaid services in the United States.[68] It should be able to garner the resources to meet its obligations and the needs of this small subset of its member population. It is being paid to do so.

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[68] Florida's Children's Medical Services Plan is operated by Sunshine Health, a wholly owned subsidiary of Centene Corporation ("Centene"). *About Us*, SUNSHINE HEALTH, https://www.sunshinehealth.com/about-us.html (last updated 2023). Centene, a Fortune 500 company, offers services and products to "nearly 1 in 15 individuals across the nation, including Medicaid and Medicare members." *Overview*, CENTENE CORPORATION, https://investors.centene.com/overview (last updated 2023). Centene's website boasts that it "is the largest Medicaid managed care organization in the country, and a leader in California, Florida, New York, and Texas, four of the largest Medicaid states." *Medicaid*, CENTENE CORPORATION, https://www.centene.com/products-and-services/state-and-national-solutions/medicaid.html (last updated 2023). In Florida, it employs over 11 thousand employees and includes subsidiaries like Sunshine Health, Wellcare, Ambetter, and Children's Medical Services Health Plan. *Florida Solutions*, CENTENE CORPORATION, https://www.centene.com/products-and-services/browse-by-state/florida.html (last updated 2023). As of December 31, 2022, Centene serviced approximately 15,272,900 Medicaid members, representing approximately 58.2% of the total Medicaid members in the country. Centene recognized approximately $144.5 billion in premium and services revenue and net earnings of $1.2 billion for the fiscal year ending 12/31/22 (NYSE: CNC), and Centene's total stockholders' equity was approximately $24.2 billion. *Centene Corporation Reports First Quarter 2023 Results*, CENTENE CORPORATION, https://investors.centene.com/2023-04-25-CENTENE-CORPORATION-REPORTS-FIRST-QUARTER-2023-RESULTS#:~:text=CENTENE%20CORPORATION%20REPORTS%20FIRST%20QUARTER%202023%20RESULTS,-

It appears from the evidence presented in this case, including the data collected by the State, and review of the relevant contracts, that Sunshine Health is not in compliance with its obligations.[69] Sunshine Health's lack of compliance stems from its inability to obtain nursing providers to deliver home-bound members necessary and clinically approved services. Care Coordinators calling on the phone imploring subcontracted home health agencies to provide prescribed staffing does not meet clinical care obligations. Children are being placed at risk. Yet the State has not declared Sunshine Health or other managed care companies out of compliance and has not used mechanisms of enforcement, such as the liquidated damages provisions.

Through inaction, the State is converting managed care contracts from a "requirements" to a "best efforts" type care relationship. This inaction, in effect, gives tacit approval to the failure to provide service. The State should hold these companies accountable.

The contracts provide several enforcement mechanisms—corrective action plans, liquidated damages, and sanctions—that would allow the State to penalize managed care plans for failing to provide medically necessary services to children. For example, in the Sunshine Health contract, the Department of Health is responsible for "imposing Sanctions for Contract violations or other non-compliance and requiring corrective actions for a violation of or any other non-compliance with this Contract and its Exhibits." (DE 965-1 at 274). The State's witnesses—Mr. Jessee and Ms. Dalton—confirmed that Florida could utilize the contractual accountability mechanisms, including by imposing liquidated damages in the amount of $2,500 per occurrence for failing to provide medically necessary services, such as PDN. Florida has never done so (at least since 2018).

CENTENE%20CORPORATION%20REPORTS&text=Increased%202023%20full%20year%20Adjusted,the%20first%20quarter%20of%202023. (last visited July 13, 2023).

[69] Sunshine Health's contract provides that "[n]othing in this Contract waives the Early and Periodic Screening, Diagnosis, and Treatment Programs (EPSDT) requirements of 42 U.S.C. § 1396d(r)(5)." (DE 965-1 at 55). EPSDT requires the provision of all medically necessary services to correct or ameliorate defects and physical and mental illnesses and conditions (DE 840, Pretrial stip., VI ¶ 6), and Sunshine Health's contract confirms that it must provide all medically necessary services to children with medical complexity, which includes all PDN authorized hours given that services are authorized only if they are medically necessary. Sunshine Health must establish "[p]rocedures for identifying patterns of over-utilization and under-utilization of services and for addressing potential problems identified as a result of these analyses[.]" (DE 965-1 at 111). Such procedures should identify the under-utilization of PDN and possible procedures for addressing the PDN problem. The contract also requires that Sunshine Health comply with network adequacy standards, including entering into service provider agreements to ensure that all covered services to enrollees are provided and "that each medically necessary covered service is accessible and provided to the enrollee with reasonable promptness[.]" (DE 965-1 at 133). Sunshine Health's contract allows it to submit a waiver request for review and approval by the Department of Health if it "is unable to demonstrate network adequacy for either timely or geographic access standards[.]" (DE 965-1 at 147).

In addition to existing terms, the State could consider adding specificity to the PDN requirements in their contracts with the Department of Health and managed care plans. While the contracts require the managed care plans to provide all medically necessary services, which is all authorized PDN, the contracts have more specific performance requirements in other service areas, such as response times for phone inquiries. Such performance standards would help the State achieve the required PDN coverage.

E. Monitor

Appointing a monitor for a limited period will assist the Parties and the Court in ensuring compliance with the injunction. I have the authority to appoint a monitor, particularly given that the State has refused to engage in efforts to craft any meaningful solutions. *See, e.g.*, *Local 28 of Sheet Metal Workers' Int'l Ass'n v. E.E.O.C.*, 478 U.S. 421, 482 (1986) ("[I]n light of the difficulties inherent in monitoring compliance with the court's orders, and especially petitioners' established record of resistance to prior state and federal court orders designed to end their discriminatory membership practices, appointment of an administrator was well within the District Court's discretion."); *City of New York v. Mickalis Pawn Shop, LLC*, 645 F.3d 114, 145 (2d Cir. 2011) ("The power of the federal courts to appoint special masters to monitor compliance with their remedial orders is well established[.]"). A monitor will serve the function of reporting on the State's compliance with my injunction. *See, e.g.*, *Local 28 of Sheet Metal Workers' Int'l Ass'n*, 478 U.S. at 481-82 (affirming as permissible a district court's "appointment of [a monitor] with broad powers to supervise [] compliance with the court's orders"); *United States v. Philip Morris USA Inc.*, 566 F.3d 1095, 1150 (D.C. Cir. 2009) (per curiam) ("a monitor may report on a defendant's 'compliance with the district court's decree and help implement that decree'").

In addition to my inherent equitable authority, Federal Rule of Civil Procedure 53 provides additional authority for my appointment of a monitor. Fed. R. Civ. P. 53(a)(1)(C) ("[A] court may appoint a master only to: . . . address . . . post-trial matters that cannot be effectively and timely addressed by an available district judge or magistrate judge of the district."). Given the breadth of data and documents requiring examination and the frequency with which I plan on monitoring compliance, it would be untenable for myself or a magistrate judge in this District to effectively and timely dive through the information without the assistance of a monitor.

Thus, I will analyze the State's progress in complying with the injunction with the aid of a monitor, who will be required to file reports with the Court every two months. The monitor will immediately report to the Court any obstruction or delay by any person with the ability to comply or influence the State's compliance with the injunction.

The anticipated term of the monitor is 24 months, assuming reasonable progress is made to comply with the injunction. I will also consider termination of the monitor and the injunction upon achievement of 90% of authorized and requested PDN on a rolling 12-month basis.[70] In addition, I reserve the right to modify the injunction to impose more stringent requirements on the State if I find that "the original purposes of the injunction are not being fulfilled in any material respect." *Sizzler Family Steak Houses v. W. Sizzlin Steak House, Inc.*, 793 F.2d 1529, 1539 (11th Cir. 1986).

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[70] I am referring to the provision of MDPI as defined in the injunction for a rolling 12-month basis.

XI. CONCLUSION

"There can be no keener revelation of a society's soul than the way in which it treats its children."

-Nelson Mandela[71]

The difficulties facing the children and parents in this case are heart wrenching. The parents' love for their children is palpable, and their actions are heroic; they jeopardize their own health, employment, and time with their other children in order to care for their medically fragile child in their home. The tragedy is that the State of Florida has programs and dedicated resources that could help these families. The Federal government spends almost two dollars for every dollar the State spends but relies upon the State to provide adequate care.

The State has chosen to provide these services through private companies in order to use competition and the market economy to promote cost savings and efficiency. But the multitude of private providers has created silos of service delivery from which children with medical complexity and their parents cannot escape. Florida needs to immediately take steps to fix this problem.

It is my firm hope and expectation that Florida's State government will work in good faith and cooperation with the United States Department of Justice. I have attempted to make the injunction entered today both specific and time limited in order to obtain tangible improvement. These children deserve equality and freedom from isolation, both as a matter of right and conscience.

It is hereby **ORDERED AND ADJUDGED** that:

1. The State of Florida, for the reasons fully set forth in this Order, is liable for policies and practices that result in the unjustifiable segregation of institutionalized children with medical complexity, and that place other children at serious risk of similar institutionalization, in violation of Title II of the Americans with Disabilities Act of 1990 ("ADA"), 42 U.S.C. §§ 12131-12134.

2. Final Judgment in favor of the United States and against the State of Florida shall be entered by separate Order, as to Count One of the Amended Complaint (DE 700).

3. An Order of Injunction shall be issued separately.

SIGNED in Chambers at West Palm Beach, Florida this 14th day of July, 2023.

Donald M. Middlebrooks
United States District Judge

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[71] Nelson Mandela, Address at the Launch of the Nelson Mandela Children's Fund (May 8, 1995), available at https://atom.nelsonmandela.org/index.php/za-com-mr-s-250.