#### No. 23-12331

## UNITED STATES COURT OF APPEALS FOR THE ELEVENTH CIRCUIT

UNITED STATES OF AMERICA,

Plaintiff-Appellee,

v.

State of Florida,  $Defendant \hbox{-} Appellant.$ 

Appeal from the United States District Court for the Southern District of Florida (Ft. Lauderdale), No. 0:12-cv-60460-DMM, Hon. Donald M. Middlebrooks

BRIEF OF THE AMERICAN ACADEMY OF PEDIATRICS, AMERICAN ASSOCIATION OF PEOPLE WITH DISABILITIES, CHILD NEUROLOGY FOUNDATION, DR. RISHI K. AGRAWAL, EXCEPTIONAL FAMILIES OF THE MILITARY, FLORIDA CHAPTER OF AMERICAN ACADEMY OF PEDIATRICS, INC., LITTLE LOBBYISTS, MENTAL HEALTH AMERICA, MUSCULAR DYSTROPHY ASSOCIATION, NATIONAL FEDERATION OF FAMILIES, PACER CENTER, ROBERT WOOD JOHNSON FOUNDATION, JUDGE DAVID L. BAZELON CENTER FOR MENTAL HEALTH LAW, CENTER FOR PUBLIC REPRESENTATION, AND NATIONAL HEALTH LAW PROGRAM AS AMICI CURIAE IN SUPPORT OF APPELLEE AND AFFIRMANCE

November 15, 2023

(counsel on inside cover)

Ira A. Burnim
Megan E. Schuller\*
THE JUDGE DAVID L. BAZELON
CENTER FOR MENTAL HEALTH LAW
1090 Vermont Avenue, N.W.
Suite 220
Washington, D.C. 20005
Phone: (202) 467-5730
irab@bazelon.org
megans@bazelon.org

Steven J. Schwartz
CENTER FOR PUBLIC
REPRESENTATION
5 Ferry Street #314
Easthampton, MA 01027
Phone: (413) 586-6024
sschwartz@cpr-ma.org

Aaron M. Panner
Rachel T. Anderson
Tiberius T. Davis\*
Nataliia Gillespie
KELLOGG, HANSEN, TODD,
FIGEL & FREDERICK, P.L.L.C.
1615 M Street, N.W., Suite 400
Washington, D.C. 20036
Phone: (202) 326-7900
apanner@kellogghansen.com
randerson@kellogghansen.com
tdavis@kellogghansen.com
ngillespie@kellogghansen.com

Martha Jane Perkins
NATIONAL HEALTH LAW
PROGRAM
1512 East Franklin Street
Suite 110
Chapel Hill, NC 20514
Phone: (919) 968-6308
perkins@healthlaw.org

\* Not admitted in the District of Columbia. Practice supervised by members of the firm.

Attorneys for Amici

# United States of America v. State of Florida, No. 23-12331 CERTIFICATE OF INTERESTED PERSONS

Under Eleventh Circuit Rules 26.1-1, 26.1-2, and 26.1-3, undersigned counsel for *amici* certify that in addition to the persons identified by Plaintiff-Appellee's and Defendant-Appellant's Certificate of Interested Persons, the following have an interest in the outcome of this case:

- 1. Agrawal, Rishi K., MD, MPH
- 2. American Academy of Pediatrics
- 3. American Association of People with Disabilities
- 4. Anderson, Rachel T., Counsel for amici
- 5. Bazelon Center for Mental Health Law
- 6. Burnim, Ira A.
- 7. Center for Public Representation
- 8. Child Neurology Foundation
- 9. Davis, Tiberius T., Counsel for *amici*
- 10. Exceptional Families of the Military
- 11. Florida Chapter of American Academy of Pediatrics, Inc.
- 12. Gillespie, Nataliia, Counsel for amici

## USCA11 Case: 23-12331 Document: 43 Date Filed: 11/15/2023 Page: 4 of 43 United States of America v. State of Florida, No. 23-12331

- 13. Kellogg, Hansen, Todd, Figel & Frederick, P.L.L.C., Counsel for amici
- 14. Little Lobbyists
- 15. Mental Health America
- 16. Muscular Dystrophy Association
- 17. National Federation of Families
- 18. National Health Law Program
- 19. PACER Center
- 20. Panner, Aaron M., Counsel for amici
- 21. Perkins, Martha Jane
- 22. Robert Wood Johnson Foundation
- 23. Schuller, Megan E.
- 24. Schwartz, Steven J.

#### CORPORATE DISCLOSURE STATEMENT

*Amici* certify that no publicly traded company or corporation has an interest in the outcome of this appeal. The entities listed above are not publicly traded and do not have stock ticker symbols.

November 15, 2023 Respectfully submitted,

/s/ Aaron M. Panner

Aaron M. Panner

### TABLE OF CONTENTS

			Page
CER	TIFI(	CATE OF INTERESTED PERSONS	C1
COF	RPORA	ATE DISCLOSURE STATEMENT	C2
TAB	BLE O	F AUTHORITIES	iii
INT	ERES	TS OF AMICI	1
STA	TEMI	ENT OF THE ISSUES	6
SUM	<b>IMAR</b>	RY OF ARGUMENT	6
ARG	HUME	ENT	9
I.	the A	District Court Properly Found That the State Violated ADA by Failing to Provide Medically Recommended sing Services in the Most Integrated Setting for Children Complex Medical Conditions	9
		Medical Conditions Under Olmstead.	11
	В.	When Public Entities Provide Necessary Support Services, Families of Children with Complex Medical Conditions Rarely Oppose Having Their Children Live at Home.	19
	C.	Providing the In-Home Nursing and Other Services Recommended by Medical Professionals and Covered by the Florida Medicaid Program Does Not Constitute a Fundamental Alteration.	24
II.		District Court Properly Exercised Its Equitable nority to Prevent Ongoing and Future Discrimination	27

CONCLUSION	30
CERTIFICATE OF COMPLIANCE	32

### TABLE OF AUTHORITIES

	Page
CASES	
Albemarle Paper Co. v. Moody, 422 U.S. 405 (1975)	29
Albra v. Advan, Inc., 490 F.3d 826 (11th Cir. 2007)	30
Armstrong v. Davis, 275 F.3d 849 (9th Cir. 2001)	30
AT&T Broadband v. Tech Commc'ns, Inc., 381 F.3d 1309 (11th Cir. 2004)	29
Black Warrior Riverkeeper, Inc. v. U.S. Army Corps of Eng'rs, 781 F.3d 1271 (11th Cir. 2015)	27
Brown v. Plata, 563 U.S. 493 (2011)	29
California v. Azar, 911 F.3d 558 (9th Cir. 2018)	28
EEOC v. Goodyear Aerospace Corp., 813 F.2d 1539 (9th Cir. 1987)	29
Fisher v. Okla. Health Care Auth., 335 F.3d 1175 (10th Cir. 2003)	27
Garrido v. Dudek, 731 F.3d 1152 (11th Cir. 2013)	28
Gonzalez v. Governor of Ga., 978 F.3d 1266 (11th Cir. 2020)	28
Kirola v. City & Cnty. of S.F., 2023 WL 2851368 (9th Cir. Apr. 10, 2023)	30

M. D. ex rel. Stukenberg v. Abbott, 907 F.3d 237 (5th Cir. 2018)	28
Moore ex rel. Moore v. Reese, 637 F.3d 1220 (11th Cir. 2011)	25
M.R. v. Dreyfus, 663 F.3d 1100 (9th Cir. 2011), amended by 697 F.3d 706 (9th Cir. 2012)	27
Nat'l Airlines, Inc., In re, 700 F.2d 695 (11th Cir. 1983)	29
Newman v. Alabama, 683 F.2d 1312 (11th Cir. 1982)	28
*Olmstead v. L.C. ex rel. Zimring, 527 U.S. 581 (1999)	4, 27
Pashby v. Delia, 709 F.3d 307 (4th Cir. 2013)	27
Pa. Prot. & Advoc., Inc. v. Pa. Dep't of Pub. Welfare, 402 F.3d 374 (3d Cir. 2005)	27
Porter v. Warner Holding Co., 328 U.S. 395 (1946)	29
Pro. Ass'n of Coll. Educators, TSTA/NEA v. El Paso Cnty. Cmty. Coll. Dist., 730 F.2d 258 (5th Cir. 1984)	29
Townsend v. Quasim, 328 F.3d 511 (9th Cir. 2003)23	3, 26
United States v. Bd. of Trs.for Univ. of Ala., 908 F.2d 740 (11th Cir. 1990)	30
United States v. Florida, 938 F.3d 1221 (11th Cir. 2019)	30
United States v. W. T. Grant Co., 345 U.S. 629 (1953)	30

Vogler v. McCarty, Inc., 451 F.2d 1236 (5th Cir. 1971)	30
STATUTES, REGULATIONS, AND RULES	
Americans with Disabilities Act of 1990, tit. II, 42 U.S.C. §§ 12131-12134	3, 5, 6
42 U.S.C. § 1396a(a)(10)(A)	25
42 U.S.C. § 1396a(a)(43)	25
42 U.S.C. § 1396d(a)(4)(B)	25
42 U.S.C. § 1396d(r)(5)	25
42 C.F.R. § 440.230(b)	25
Fed. R. App. P. 29(a)(4)(E)	1
OTHER MATERIALS	
Agency for Health Care Admin., State of Florida, Statewide  Medicaid Managed Care – Medicaid Fair Hearing, https://bit.ly/47oBJud (last visited Nov. 15, 2023)	19
Carman Caicedo, Health and Functioning of Families of Children With Special Health Care Needs Cared for in Home Care, Long-term Care, and Medical Day Care Setti 36 J. Developmental & Behav. Pediatrics 352 (June 2015	
Children with Disabilities: Deprivation of Liberty in the Name of Care and Treatment, Hum. Rts. Watch (Mar. 7, 2017), https://bit.ly/3FW9Ihb	

Carolyn C. Foster et al.:
Home Health Care For Children With Medical Complexity:  Workforce Gaps, Policy, And Future Directions,  38 Health Affairs 987 (June 2019),  https://bit.ly/3QBqc3j
Improving Support for Care at Home: Parental Needs and Preferences When Caring for Children With Medical Complexity, 36 J. Pediatric Health Care 154 (Apr. 2022) 15
Sandra L. Friedman et al., Out-of-Home Placement for Children and Adolescents With Disabilities—Addendum: Care Options for Children and Adolescents With Disabilities and Medical Complexity, 138 Pediatrics 1 (Dec. 2016), https://bit.ly/3QsJzvq
Philip S. Goldman et al., Institutionalisation and Deinstitutionalisation of Children 2: A Systematic and Integrative Review of Evidence Regarding Effects on Development, 4 Lancet Psychiatry 606 (Aug. 2020), https://bit.ly/465xqCs
Dennis Z. Kuo et al., Care Coordination for Children with  Medical Complexity: Whose Care Is It, Anyway?,  141 J. Pediatrics (Suppl. 3, Mar. 2018), https://bit.ly/3Qw6Tsc22
Lori A. Legano et al., <i>Maltreatment of Children With Disabilities</i> , 147 Pediatrics 401 (May 2021), https://bit.ly/3QWILjG14
Roy Maynard et al., Home Health Care Availability and Discharge Delays in Children With Medical Complexity, 143 Pediatrics 1 (2019), https://bit.ly/40B5aXd
Garey Noritz, Commentary, The Moral Imperative of Home Health Care for Children: Beyond the Financial Case, 143 Pediatrics 1 (Jan. 2019), https://bit.ly/3FW9BSN11, 12
Theodore E. Schall et al., Safe Work-Hour Standards for Parents of Children With Medical Complexity, 174 JAMA Pediatrics 7 (Nov. 2019

Steven J. Schwartz et al., Realizing the Promise of Olmstead:  Ensuring the Informed Choice of Institutionalized Individuals With Disabilities to Receive Services in the Most Integrated Setting, 40 J. Legal Med. 63, https://bit.ly/3QV32X2	22
Sarah A. Sobotka et al.:	
Attributable Delay of Discharge for Children With Long-Term Mechanical Ventilation, 212 J. Pediatrics 166 (Sept. 2019), https://bit.ly/47vDo0m	21
Prolonged Hospital Discharge for Children With Technology Dependency: A Source of Health Care Disparities, 36 Pediatrics Ann. 1 (Oct. 2017), https://bit.ly/3QAF81F	20
Valerie Boebel Toly et al., Caring for Technology-Dependent Children at Home: Problems and Solutions Identified by Mothers, 50 Applied Nursing Rsch. 1 (Dec. 2019), https://bit.ly/3FW9OW5	20
Trauma Caused by Separation of Children from Parents – A Tool for Lawyers, Am. Bar Ass'n (Jan. 2020), https://bit.ly/3QS62Ds	14

#### INTERESTS OF AMICI<sup>1</sup>

Amici are pediatric medical experts, professional medical associations, and public health, family, and disability advocacy organizations that represent or work on behalf of millions of people with disabilities, including children with medically complex conditions, and a national philanthropic organization committed to advancing health equity.

The American Academy of Pediatrics ("AAP"), founded in 1930, is an organization of 67,000 pediatricians, pediatric medical subspecialists, and pediatric surgical specialists committed to the optimal physical, mental, and social health and wellbeing for all infants, children, adolescents, and young adults. As one facet of this mission, AAP clinical guidance supports home health care as a patient- and family-centered delivery system that can be integrated within a comprehensive care program.

<sup>&</sup>lt;sup>1</sup> Under Federal Rule of Appellate Procedure 29(a)(4)(E), *amici* declare that no party's counsel authored this brief in whole or in part; no party or party's counsel contributed money intended to fund preparing or submitting the brief; and no person—other than *amici* or their counsel—contributed money intended to fund preparing or submitting this brief. All parties have consented to the filing of this brief.

The American Association of People with Disabilities is a national disability-led and cross-disability rights organization that advocates for equal opportunity and independent living for over 60 million Americans with disabilities.

Child Neurology Foundation supports the 1-in-5 children and young adults living with neurologic conditions in the United States, their caregivers, and their clinicians, including supporting people-centered, dignified care so that every child can reach their full potential.

Dr. Rishi K. Agrawal, MD, MPH, is a physician and researcher who joins this amicus brief in his individual capacity. Dr. Agrawal is also an Attending Physician at Lurie and La Rabida Children's Hospitals in Chicago, a Professor of Pediatrics at Northwestern University Feinberg School of Medicine, and the founder of the Complex Care Special Interest Group.

Exceptional Families of the Military connects military families with disabilities and special health care needs and works with them to identify areas of improvement and achieve long-lasting changes in the laws and regulations that affect them.

The Florida Chapter of American Academy of Pediatrics, Inc. is a non-profit member-based organization that advocates for quality health care for all children and supports the pediatric medical professionals who care for them.

Little Lobbyists is a family-led organization that advocates for children with complex medical needs and disabilities and unequivocally supports the right to live at home over unnecessary institutionalization in accordance with the Americans with Disabilities Act.

Mental Health America, founded in 1909, is a leading communitybased non-profit dedicated to addressing the needs of those living with mental illness and promoting the mental health of all.

The Muscular Dystrophy Association ("MDA") is the number one voluntary health organization in the United States for people living with muscular dystrophy, ALS, and related neuromuscular diseases. MDA's mission is to empower the people they serve to live longer, more independent lives.

The National Federation of Families is a national advocacy organization that serves as the national voice for families of children who

experience emotional, behavioral, mental health, and substance use challenges—across the lifespan.

PACER Center is a non-profit organization that has worked nationally for 46 years to enhance the quality of life for children with disabilities, including complex medical conditions.

The Robert Wood Johnson Foundation is the nation's largest philanthropic organization dedicated solely to health. It supports efforts to build a national Culture of Health rooted in equity that provides every individual with a fair and just opportunity for health and wellbeing.

The Judge David L. Bazelon Center for Mental Health Law is a national organization that advocates for the civil rights, full inclusion, and equality of adults and children with mental disabilities.

Center for Public Representation is a national legal advocacy organization that has been enforcing the rights of people with disabilities, and fighting to ensure they have access to the critical health care services they need to live and participate in their own communities, for almost 50 years.

The National Health Law Program is a national legal advocacy organization that works on behalf of low-income individuals and families

to advocate for a health care system that will ensure all people have access to quality and comprehensive health care.

Amici have an interest in preserving the right of children with complex medical conditions to live with their families—in the most integrated setting, as required by the Americans with Disabilities Act and Olmstead v. L.C. ex rel. Zimring, 527 U.S. 581, 597 (1999).

Accordingly, *amici* submit this brief to urge the Eleventh Circuit to affirm the district court's judgment.

#### STATEMENT OF THE ISSUES

- 1. Whether the district court properly found that Florida failed to provide necessary health care and other services to children with complex medical conditions in the most integrated setting, in violation of the integration mandate of the Americans with Disabilities Act and Olmstead?
- 2. Whether the district court acted within its broad equitable discretion in ordering a remedy that would prevent future and ongoing discrimination by Florida against children with complex medical conditions?

#### SUMMARY OF ARGUMENT

Florida's implementation of Medicaid and other public service programs has resulted in the unnecessary institutionalization of children with complex medical conditions, in violation of Title II of the Americans with Disabilities Act of 1990 ("ADA"). Despite the federal mandate that these children live in the most integrated setting appropriate for their needs, the State routinely fails to provide the services these children require and to which they are legally entitled. This failure is the direct

cause of the unnecessary institutionalization of children in nursing facilities and their resultant separation from their families.

Voluminous scholarly and professional literature supports the district court's conclusion—firmly grounded in the record—that Florida's practices violate the ADA because children are regularly deprived of recommended and necessary at-home nursing and other services, such as in-home medical equipment. The literature establishes that it is almost always more appropriate and more effective for children with complex medical needs to be cared for at home than in an institution. Similarly, research shows that parents want to care for their children at home but are often denied the services needed to do so.

Consistent with this learning, the district court found, based on the record evidence, that the children in Florida's nursing facilities could be appropriately cared for at home and that generally parents would prefer to care for their children at home, assuming Florida provided the private duty nursing ("PDN") and other services that its own policies and contracts require. The record also supports the district court's finding that requiring the State to ensure these services are actually provided does not constitute a fundamental alteration of the State's programs.

Once the district court properly found serious and ongoing discrimination in violation of the ADA, it had broad discretion to fashion an equitable remedy. This is particularly true here, where the United States is enforcing a federal statute designed to remedy and prevent discrimination. The district court acted well within that broad discretion by adopting a remedy that addresses ongoing segregation and prevents future discrimination. Despite Florida's criticism, the fact that many children with complex medical conditions benefit from this remedy, even though they are at serious risk of future institutionalization rather than currently institutionalized, does not render the remedy overbroad.

This Court should affirm.

#### **ARGUMENT**

I. The District Court Properly Found That the State Violated the ADA by Failing to Provide Medically Recommended Nursing Services in the Most Integrated Setting for Children with Complex Medical Conditions.

In Olmstead v. L.C. ex rel. Zimring,<sup>2</sup> the Supreme Court held that a state's failure to provide home- and community-based services, resulting in unnecessary institutionalization, is discrimination that violates the ADA.<sup>3</sup> The Court explained that this rule reflects two evident congressional judgments. "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." "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." Scholarly and professional literature, including by doctors

<sup>&</sup>lt;sup>2</sup> 527 U.S. 581, 587 (1999).

<sup>&</sup>lt;sup>3</sup> *Id.* at 597-603, 607.

<sup>&</sup>lt;sup>4</sup> *Id.* at 600.

<sup>&</sup>lt;sup>5</sup> *Id.* at 601.

who treat children with complex medical conditions, confirms that those harms are a reality for children denied needed home- and community-based services and unnecessarily institutionalized in nursing facilities.

To remedy these harms, the ADA imposes an affirmative obligation on states to provide services to persons with disabilities in the most integrated setting appropriate to their needs.<sup>6</sup> States must offer individuals services at home or in community settings if: (1) home or community placement is "appropriate"; (2) the individual (or parents, in case of a minor) is "not opposed" to the transition; and (3) "the placement can be reasonably accommodated" by the state—unless the state can establish that the remedy would cause a "fundamental alteration" of the state's services and programs.<sup>7</sup> Here, the medical literature strongly supports the district court's record-based finding that each element of the Olmstead standard is met.

<sup>&</sup>lt;sup>6</sup> See id. at 607.

 $<sup>^7</sup>$  Id. at 587, 603 (cleaned up).

# A. The Family Home Is the Most Integrated and Appropriate Setting for Children with Complex Medical Conditions Under *Olmstead*.

Under *Olmstead*'s first element, courts must consider whether community placement is "appropriate" for the individual.<sup>8</sup> Both the ADA and *Olmstead* mandate that every person be served in the most integrated setting appropriate to meet their needs. For children, that is living with their family.

Living at home provides children with substantial benefits. Families carry out such important functions as nurturing, protection, and socializing.<sup>9</sup> And a child's kinship network plays an essential role in helping the child integrate in their communities through participation in social, economic, cultural, and religious activities.<sup>10</sup> Put simply, both children and their families "thrive in home environments."<sup>11</sup>

<sup>&</sup>lt;sup>8</sup> *Id.* at 587.

<sup>&</sup>lt;sup>9</sup> Philip S. Goldman et al., Institutionalisation and Deinstitutionalisation of Children 2: A Systematic and Integrative Review of Evidence Regarding Effects on Development, 4 Lancet Psychiatry 606, 609 (Aug. 2020), https://bit.ly/465xqCs.

<sup>&</sup>lt;sup>10</sup> *Id.* at 608.

<sup>&</sup>lt;sup>11</sup> See Garey Noritz, Commentary, The Moral Imperative of Home Health Care for Children: Beyond the Financial Case, 143 Pediatrics 1, 2 (Jan. 2019), https://bit.ly/3FW9BSN.

The essential functions that a family performs improve children's developmental outcomes. As one example, a stable family environment is known to promote a child's school performance, as well as to positively affect the child's health status.<sup>12</sup> And a child's removal from an institution and their placement in a family setting is associated with significant, albeit incomplete, developmental recovery.<sup>13</sup> Importantly, the shorter the duration of any institutionalization, the better the outcomes.<sup>14</sup>

These principles apply with particular force to children with complex medical needs. Such children, who often face stigma and discrimination, are disproportionately represented in institutions and deprived of the essential benefits that living with their families would provide. Their return to their families and communities is therefore paramount and should be achieved as early as possible. 16

 $<sup>^{12}</sup>$  Supra note 9, at 609.

<sup>&</sup>lt;sup>13</sup> *Id.* at 608.

 $<sup>^{14}</sup>$  *Id*.

<sup>&</sup>lt;sup>15</sup> *Id.* at 613.

 $<sup>^{16}</sup>$  Supra note 11, at 2.

The many harmful effects of institutionalization are caused by several factors. Even the "best congregate care setting[s]" have factors that "render [them] potentially harmful to children."<sup>17</sup> These factors include: "(1) large ratio of children to caregivers; (2) absence of a primary caregiver for each child; (3) turnover of caregivers; (4) inferior cognitive, linguistic, and socioemotional stimulation; (5) regimented schedules and lack of spontaneity in child-adult interactions; and (6) limited peer-to-peer interaction."<sup>18</sup> As the United States' expert Dr. Carolyn Foster testified, these harmful factors are "inherent" to congregate care facilities.<sup>19</sup> Additionally, living in an institution, like a nursing facility, can harm children by inhibiting independent functioning and causing fear-based regression.<sup>20</sup>

<sup>&</sup>lt;sup>17</sup> Sandra L. Friedman et al., Out-of-Home Placement for Children and Adolescents With Disabilities—Addendum: Care Options for Children and Adolescents With Disabilities and Medical Complexity, 138 Pediatrics 1, 2 (Dec. 2016), https://bit.ly/3QsJzvq.

<sup>&</sup>lt;sup>18</sup> *Id.* at 2-3.

 <sup>&</sup>lt;sup>19</sup> Mem. Op. & Order, *United States v. Florida*, No. 12-cv-60460
 (S.D. Fla. July 14, 2023), Doc. 1170, at 50.

<sup>&</sup>lt;sup>20</sup> Sarah A. Sobotka et al., *Prolonged Hospital Discharge for Children With Technology Dependency: A Source of Health Care Disparities*, 46 Pediatrics Ann. e365, e367-e368 (Oct. 2017), https://bit.ly/3QAF81F.

The risk of neglect and abuse, including sexual abuse, is higher for institutionalized children with disabilities than for children with disabilities who live with their families.<sup>21</sup> One reason is "the increased number of caregivers that children with disabilities encounter."<sup>22</sup> In addition, removal of a child from their home and their placement in a non-family setting can cause significant psychological trauma.<sup>23</sup>

Importantly, no significant differences have been found in the overall physical health of children with complex medical conditions living in long-term care facilities, like the nursing facilities here, versus those living at home.<sup>24</sup> In other words, children need not—and should not—be

 $<sup>^{21}</sup>$  Children with Disabilities: Deprivation of Liberty in the Name of Care and Treatment, Hum. Rts. Watch (Mar. 7, 2017), https://bit.ly/3FW9Ihb.

<sup>&</sup>lt;sup>22</sup> See Lori A. Legano et al., Maltreatment of Children With Disabilities, 147 Pediatrics 401, 405 (May 2021), https://bit.ly/3QWILjG.

<sup>&</sup>lt;sup>23</sup> Trauma Caused by Separation of Children from Parents – A Tool for Lawyers, Am. Bar Ass'n (Jan. 2020) (discussing scholarship), https://bit.ly/3QS62Ds.

<sup>&</sup>lt;sup>24</sup> See Carman Caicedo, Health and Functioning of Families of Children With Special Health Care Needs Cared for in Home Care, Longterm Care, and Medical Day Care Settings, 36 J. Developmental & Behav. Pediatrics 352, 356 (June 2015); see also Doc. 1170, at 51.

separated from their parents and home in order to receive needed medical services.

Medical literature recognizes that, with proper support, children with complex medical conditions can and do live safely and healthily with their families. Technological advances<sup>25</sup> and access to nursing care allow children to have their medical needs met while living at home.<sup>26</sup> In a study of 185 discharged children with complex medical conditions, only one child was re-institutionalized because the home setting could not support them.<sup>27</sup> And there is broad agreement that "[m]ost families . . . have expertise about their children's needs . . . and make decisions that support their children's best interests."<sup>28</sup>

As the district court correctly concluded based on the evidence before it, home settings are appropriate for children with complex

<sup>&</sup>lt;sup>25</sup> Carolyn C. Foster et al., Improving Support for Care at Home: Parental Needs and Preferences When Caring for Children With Medical Complexity, 36 J. Pediatric Health Care 154, 155 (Apr. 2022).

<sup>&</sup>lt;sup>26</sup> Supra note 20.

<sup>&</sup>lt;sup>27</sup> Roy Maynard et al., *Home Health Care Availability and Discharge Delays in Children With Medical Complexity*, 143 Pediatrics 1, 5 (2019), https://bit.ly/40B5aXd.

 $<sup>^{28}</sup>$  Supra note 17, at 3.

medical conditions.<sup>29</sup> And the court properly rejected the idea that appropriateness requires an assessment of, or depends on, the physical layout of every home, whether the child has a separate room, or the presence of two parents.<sup>30</sup> The district court properly found that a number of children are currently institutionalized in nursing facilities solely because the needed PDN is unavailable, and that, had those services been provided to them, the children could be living with their families.<sup>31</sup> Furthermore, the record shows that the problem is commonplace and not new: a number of children were previously institutionalized for a period simply due to a lack of nursing services, even though their homes would otherwise have been appropriate.<sup>32</sup>

In addition to Florida's failure to provide necessary PDN services, the district court found that Florida's failure to provide children with

<sup>&</sup>lt;sup>29</sup> Doc. 1170, at 38-39.

<sup>&</sup>lt;sup>30</sup> *Id*.

 $<sup>^{31}</sup>$  See id. at 26, 36-37, 59-60 (identifying at least nine specific children with medical complexity currently institutionalized solely because of lack of PDN).

<sup>&</sup>lt;sup>32</sup> See, e.g., id. at 28 (describing how Jeffrey was institutionalized for years because of a lack of PDN); id. at 36 (describing multiple children whose home environments were appropriate but children had to be institutionalized because of unreliable PDN services).

necessary medical equipment also interferes with their ability to live with their families.<sup>33</sup> The iBudget waiver, Florida's program designed to provide for home modifications, medical equipment, and other non-PDN support, plays an important role in bringing children home.<sup>34</sup> But iBudget has a years-long waitlist, creating yet another obstacle for families who want to care for their children at home.<sup>35</sup>

Florida's assertion that the district court erred by failing to question the suitability of each family home in which the children would live and receive care is meritless.<sup>36</sup> The district court addressed the *Olmstead* inquiry—whether children's homes are "appropriate" placements for their needs—and found that they were. The literature makes clear that the family home is a suitable and appropriate setting in which to receive care, and the district court's examination of the evidence before it amply supported that conclusion.

<sup>&</sup>lt;sup>33</sup> *Id.* at 42.

<sup>&</sup>lt;sup>34</sup> *Id.* at 41-42.

 $<sup>^{35}</sup>$  *Id*.

<sup>&</sup>lt;sup>36</sup> Florida Opening Br. at 19-20, 22 ("Fla. Br.").

The district court properly found that a number of children are currently institutionalized because adequate PDN is unavailable, and that had those services been provided to them, the children could be living at home with their families.<sup>37</sup> And although a few parents testified that they were not yet ready to bring their children home immediately due to personal circumstances, the district court aptly concluded that "[s]uch atypical cases cannot support a finding that most families' real-world circumstances preclude them from caring for their children at home."<sup>38</sup> Indeed, even in those outlier cases, the families may be ready to bring their children home by the time necessary in-home services are provided by Florida and the children are ready for discharge.

Moreover, included in the district court's remedy is an individualized, professional evaluation of the suitability of the family's home through the process of Care Coordination,<sup>39</sup> a service provided by a trained individual, "usually a nurse or social worker," that facilitates

<sup>&</sup>lt;sup>37</sup> See Doc. 1170, at 26, 36-37, 59-60.

<sup>&</sup>lt;sup>38</sup> *Id.* at 57.

<sup>&</sup>lt;sup>39</sup> *Id.* at 46-47.

families' caring for their children at home.<sup>40</sup> As part of helping arrange care at home—including by facilitating PDN, helping families obtain medical equipment, and managing access to therapies a child may require<sup>41</sup>—Care Coordination staff make sure that the child's home is an appropriate care setting before they are discharged.<sup>42</sup>

B. When Public Entities Provide Necessary Support Services, Families of Children with Complex Medical Conditions Rarely Oppose Having Their Children Live at Home.

The second *Olmstead* element requires that the provision of services in a home- or community-based setting not be opposed by the child's family.<sup>43</sup> These services, including PDN and necessary medical equipment, are critical to children living with their families. If Florida

<sup>&</sup>lt;sup>40</sup> *Id.* at 38; *see id.* at 6 (explaining that Care Coordination is among the services provided by the State's managed care plans serving children with complex medical needs in Florida).

<sup>&</sup>lt;sup>41</sup> *Id.* at 18, 38-39.

<sup>&</sup>lt;sup>42</sup> See generally Agency for Health Care Admin., State of Florida, Statewide Medicaid Managed Care – Medicaid Fair Hearing, https://bit.ly/47oBJud (last visited Nov. 15, 2023).

<sup>&</sup>lt;sup>43</sup> 527 U.S. at 587.

provided the necessary support, parents would "overwhelmingly" choose to have their children at home.<sup>44</sup>

Academic literature strongly supports the district court's finding of non-opposition. "Most families want to care for their children in their home... and make decisions that support their children's best interests." Additionally, "there is evidence that raising a child with chronic medical conditions has positive effects on family cohesion and appreciation for life." Support services allow a family's home life to become "normalized," which makes "parents feel competent in caring for the complex healthcare needs of their children . . . and have greater confidence in their parenting skills." By contrast, institutional care is associated with "negative parental outcomes such as stress, post-

<sup>&</sup>lt;sup>44</sup> Doc. 1170, at 58-59.

<sup>&</sup>lt;sup>45</sup> *Supra* note 17, at 3.

<sup>&</sup>lt;sup>46</sup> *Id*.

<sup>&</sup>lt;sup>47</sup> Valerie Boebel Toly et al., Caring for Technology-Dependent Children at Home: Problems and Solutions Identified by Mothers, 50 Applied Nursing Rsch. 1, 1-2 (Dec. 2019), https://bit.ly/3FW9OW5.

traumatic stress disorder, depression, and anxiety."<sup>48</sup> It also disrupts parent-child bonding.<sup>49</sup>

Without needed services, parents face significant challenges and burdens in caring for their children at home. Families of course have non-caregiving responsibilities, such as employment, care of other family members, and maintenance of the home.<sup>50</sup> To provide the necessary care, families may be forced to compromise these other responsibilities in order to spend the necessary time—on average 52 hours per week—caring for their children with complex medical conditions.<sup>51</sup> Given these challenges, families often depend on needed services to make home care work.<sup>52</sup>

Professional research identifies another important dimension of measuring opposition: informed choice. Families, after all, may not

<sup>&</sup>lt;sup>48</sup> Sarah A. Sobotka et al., Attributable Delay of Discharge for Children With Long-Term Mechanical Ventilation, 212 J. Pediatrics 166, 166 (Sept. 2019), https://bit.ly/47vDo0m.

<sup>&</sup>lt;sup>49</sup> *Id*.

<sup>&</sup>lt;sup>50</sup> Theodore E. Schall et al., Safe Work-Hour Standards for Parents of Children With Medical Complexity, 174 JAMA Pediatrics 7, 7 (Jan. 2020).

<sup>&</sup>lt;sup>51</sup> *Id*.

 $<sup>^{52}</sup>$  Supra note 17, at 3.

know that services comparable to those their children receive in an institution can be provided in their home.<sup>53</sup> Professionals agree that, without adequate information, support, and time, families cannot make an informed choice about the best care setting for their child.<sup>54</sup> Real or perceived opposition is therefore often due to a failure to engage with and inform families in a meaningful way. Importantly, engaging with families to help them make an informed choice not only opens up the possibility of children living at home, it can also "positively impact" the care that children ultimately receive because it relies on treating parents as partners in providing successful care.<sup>55</sup>

The district court heard from many parents who want their children with complex medical conditions to live at home, though some explicitly stated that they need PDN or other support services to do so. The court concluded that "many families were actively in the process of

<sup>&</sup>lt;sup>53</sup> Steven J. Schwartz et al., Realizing the Promise of Olmstead: Ensuring the Informed Choice of Institutionalized Individuals With Disabilities to Receive Services in the Most Integrated Setting, 40 J. Legal Med. 63, 72 (May 2020), https://bit.ly/3QV32X2.

<sup>&</sup>lt;sup>54</sup> *Id.* at 85, 92.

<sup>&</sup>lt;sup>55</sup> See Dennis Z. Kuo et al., Care Coordination for Children With Medical Complexity: Whose Care Is It, Anyway?, 141 J. Pediatrics s226-s228 (Suppl. 3, Mar. 2018), https://bit.ly/3Qw6Tsc.

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."56

Although Florida asserts that certain families "oppose" their children living at home, such hesitancy is almost always based on the unavailability of needed support services.<sup>57</sup> But opposition cannot be reliably measured without reference to whether those families would be opposed *if necessary services were provided*. And the district court emphasized that "[t]he relevant question is whether service recipients with disabilities would choose community-based services if they were actually available and accessible."<sup>58</sup> It properly concluded that Florida's failure to meaningfully inform and engage with families left parents who

<sup>&</sup>lt;sup>56</sup> Doc. 1170, at 61.

<sup>&</sup>lt;sup>57</sup> See Fla. Br. at 22-23.

<sup>&</sup>lt;sup>58</sup> Doc. 1170, at 56; *cf. Townsend v. Quasim*, 328 F.3d 511, 517 (9th Cir. 2003) (the fact that the required services were only provided in an institution, not individuals' homes, did not negate a finding of liability under *Olmstead*).

preferred their children to be at home without an understanding of how to achieve that goal.<sup>59</sup>

In sum, professional research and the record provide ample support for the conclusion that families are not only unopposed but are "ready and willing" to bring their children home.<sup>60</sup>

C. Providing the In-Home Nursing and Other Services Recommended by Medical Professionals and Covered by the Florida Medicaid Program Does Not Constitute a Fundamental Alteration.

Olmstead's final prong requires public entities to provide in-home and community-based services when such services can reasonably be provided—unless the state can show that such accommodation would fundamentally alter the public entity's service system. As the United States' brief ably explains, that prong is satisfied because Florida can provide such accommodation by, for example, assuring that the children get the PDN services they need.

<sup>&</sup>lt;sup>59</sup> Doc. 1170, at 39-40.

<sup>60</sup> Fla. Br. at 22.

<sup>&</sup>lt;sup>61</sup> 527 U.S. at 587.

<sup>&</sup>lt;sup>62</sup> U.S. Opening Br. at 29-33.

There is no fundamental alteration here because in-home skilled nursing, Care Coordination, and other services children need to be cared for by their families are ones that Florida already requires its managed care entities to deliver. Florida's Medicaid program has long provided for nursing services that recommended bv medical in-home are professionals, as is required by federal law.<sup>63</sup> Similarly, Florida has long imposed a requirement that Care Coordination be provided to help families care for their children at home. To assure that these services are furnished at the level recommended by medical professionals, Florida contracts with managed care plans who coordinate and deliver the services.<sup>64</sup>

Providing these services in the prescribed amount to children living at home and at serious risk of institutionalization is not a fundamental alteration. Florida, through its contracted medical professionals, has

<sup>&</sup>lt;sup>63</sup> Doc. 1170, at 30-31, 34; see 42 U.S.C. §§ 1396a(a)(10)(A), 1396a(a)(43), 1396d(a)(4)(B), 1396d(r)(5); Moore ex rel. Moore v. Reese, 637 F.3d 1220, 1261 (11th Cir. 2011) (Under state Medicaid plans "a state still must ensure that each required service is 'sufficient in amount, duration, and scope to reasonably achieve its purpose.") (quoting 42 C.F.R. § 440.230(b)).

<sup>&</sup>lt;sup>64</sup> Doc. 1170, at 31.

already found the children to be eligible for these services, and their provision is required under the State's own programs.<sup>65</sup> The district court's order does no more than require Florida to adequately fund and deliver services that it has already promised to provide. If such a requirement amounted to a fundamental alteration, it would render the ADA and the Supreme Court's *Olmstead* decision entirely ineffectual.<sup>66</sup>

Although Florida complains that nursing shortages are an obstacle to increasing PDN hours, a recent study demonstrates that increasing nurses' pay can address the shortage of PDN for children with complex medical needs.<sup>67</sup> The actions necessary to remedy discrimination under Olmstead will often require expenditures of public funds. However, that alone does not render the remedy a fundamental alteration, as four circuits have confirmed.<sup>68</sup> As the Tenth Circuit astutely observed, "[i]f

<sup>&</sup>lt;sup>65</sup> *Id.* at 30-31, 34.

<sup>&</sup>lt;sup>66</sup> See Townsend, 328 F.3d at 517, 519.

<sup>67</sup> Carolyn C. Foster et al., Home Health Care For Children With Medical Complexity: Workforce Gaps, Policy, And Future Directions, 38 Health Affairs 987, 989-90 (June 2019), https://bit.ly/3QBqc3j.

<sup>&</sup>lt;sup>68</sup> See Olmstead, 527 U.S. at 603-04; Pashby v. Delia, 709 F.3d 307, 323 (4th Cir. 2013) ("[B]udgetary concerns do not alone sustain a fundamental alteration defense."); M.R. v. Dreyfus, 663 F.3d 1100, 1118 (9th Cir. 2011), amended by 697 F.3d 706 (9th Cir. 2012) (same); Pa. Prot.

every alteration in a program or service that required the outlay of funds were tantamount to a fundamental alteration, the ADA's integration mandate would be hollow indeed."<sup>69</sup> Merely requiring Florida to provide the resources it is obligated to deliver under state and federal law is not a fundamental alteration.

## II. The District Court Properly Exercised Its Equitable Authority to Prevent Ongoing and Future Discrimination.

After properly finding that Florida discriminated against children with complex medical needs, the district court used its "broad discretion to fashion an equitable remedy." This Court reviews "the decision to grant an injunction and the scope of the injunction for abuse of

<sup>&</sup>amp; Advoc., Inc. v. Pa. Dep't of Pub. Welfare, 402 F.3d 374, 380 (3d Cir. 2005) ("Though clearly relevant, budgetary constraints alone are insufficient to establish a fundamental alteration defense."); Fisher v. Okla. Health Care Auth., 335 F.3d 1175, 1183 (10th Cir. 2003) (same).

<sup>&</sup>lt;sup>69</sup> Fisher, 335 F.3d at 1183.

<sup>&</sup>lt;sup>70</sup> Black Warrior Riverkeeper, Inc. v. U.S. Army Corps of Eng'rs, 781 F.3d 1271, 1290 (11th Cir. 2015).

discretion."<sup>71</sup> Even when a state is the defendant, this Court's review is "very narrow" and "deferential."<sup>72</sup>

The district court acted well within its discretion. As explained, record evidence shows that many of the children who are currently institutionalized could be cared for at home if Florida provided the needed services.<sup>73</sup> The evidence also shows that many children are at serious risk of being sent to a nursing facility due to Florida's failure to provide the needed services.

Failing to acknowledge the district court's broad discretion, Florida argues that the injunction is overbroad.<sup>74</sup> Of course, equitable remedies must be tailored to the injuries at issue, which the court's injunction is.<sup>75</sup> But an injunction "is not necessarily made overbroad by extending

<sup>&</sup>lt;sup>71</sup> Garrido v. Dudek, 731 F.3d 1152, 1158 (11th Cir. 2013) (reviewing injunction against the Florida Agency for Health Care Administration).

<sup>&</sup>lt;sup>72</sup> Gonzalez v. Governor of Ga., 978 F.3d 1266, 1270 (11th Cir. 2020).

<sup>&</sup>lt;sup>73</sup> See supra Part I.

<sup>&</sup>lt;sup>74</sup> Fla. Br. at 42-46.

<sup>&</sup>lt;sup>75</sup> M. D. ex rel. Stukenberg v. Abbott, 907 F.3d 237, 271-72 (5th Cir. 2018); see also California v. Azar, 911 F.3d 558, 584 (9th Cir. 2018) (The injunction "must be no broader and no narrower than necessary to redress the injury shown."); Newman v. Alabama, 683 F.2d 1312, 1319 (11th Cir. 1982).

benefit or protection to persons other than prevailing parties in the lawsuit . . . if such breadth is necessary to give prevailing parties the relief to which they are entitled."<sup>76</sup>

The equities favor the relief in this case, where the United States is seeking to vindicate the public's interest in the enforcement of federal anti-discrimination laws. When a case is brought to vindicate the public interest, "[the district court's] equitable powers assume an even broader and more flexible character."<sup>77</sup> In particular, district courts have "broad discretion in the fashioning of orders to remedy past and present discrimination."<sup>78</sup> Indeed, systemic injunctions against state actors have

<sup>&</sup>lt;sup>76</sup> Pro. Ass'n of Coll. Educators, TSTA/NEA v. El Paso Cnty. Cmty. Coll. Dist., 730 F.2d 258, 273-74 (5th Cir. 1984); accord Brown v. Plata, 563 U.S. 493, 531 (2011).

<sup>&</sup>lt;sup>77</sup> AT&T Broadband v. Tech Commc'ns, Inc., 381 F.3d 1309, 1316 (11th Cir. 2004) (brackets in original) (quoting Porter v. Warner Holding Co., 328 U.S. 395, 398 (1946)).

<sup>&</sup>lt;sup>78</sup> In re Nat'l Airlines, Inc., 700 F.2d 695, 697 (11th Cir. 1983) (per curiam); see also Albemarle Paper Co. v. Moody, 422 U.S. 405, 421 (1975) (stating that the Civil Rights Act of 1964 was "intended to give the courts wide discretion [in] exercising their equitable powers to fashion the most complete relief possible"); EEOC v. Goodyear Aerospace Corp., 813 F.2d 1539, 1543 (9th Cir. 1987) (finding that settlement of individuals did not moot broad agency injunctive relief because "the [agency] promotes public policy and seeks to vindicate rights belonging to the United States as sovereign"); Albra v. Advan, Inc., 490 F.3d 826, 829 (11th Cir. 2007)

been affirmed under the ADA and Rehabilitation Act of 1973.<sup>79</sup> Here, the equities strongly favor an injunction that will "prevent future discrimination and remedy the effects of past discrimination."<sup>80</sup>

The district court's injunction is well within its discretion.

#### CONCLUSION

This Court should affirm the district court's judgment.

<sup>(</sup>per curiam) (the ADA "provides the same remedies" as the Civil Rights Act of 1964 and Rehabilitation Act of 1973); *United States v. Florida*, 938 F.3d 1221, 1226-30 (11th Cir. 2019) (same).

<sup>&</sup>lt;sup>79</sup> See, e.g, United States v. Bd. of Trs. for Univ. of Ala., 908 F.2d 740, 742-44, 752 (11th Cir. 1990) (affirming an injunction that required a university to provide auxiliary aids to disabled students regardless of financial aid status and remanding to remedy insufficient busing accommodations, even though only one student complained); Armstrong v. Davis, 275 F.3d 849, 854, 870-72, 879 (9th Cir. 2001) (affirming, in part, a systemwide injunction modifying parole board policies), abrogated on other grounds by Kirola v. City & Cnty. of S.F., 2023 WL 2851368 (9th Cir. Apr. 10, 2023).

<sup>&</sup>lt;sup>80</sup> Vogler v. McCarty, Inc., 451 F.2d 1236, 1238 (5th Cir. 1971) (emphasis added); see also United States v. W. T. Grant Co., 345 U.S. 629, 633 (1953) ("The purpose of an injunction is to prevent future violations.").

Dated: November 15, 2023

Ira A. Burnim

Megan E. Schuller\*

THE JUDGE DAVID L. BAZELON

CENTER FOR MENTAL HEALTH LAW
1090 Vermont Avenue, N.W.

Suite 220

Washington, D.C. 20005

Phone: (202) 467-5730

irab@bazelon.org

Aaron M. Panner
Rachel T. Anderso
Nataliia Gillespie
KELLOGG, HANSEN
1615 M Street, N.
Washington, D.C.
Phone: (202) 326-

Steven J. Schwartz
CENTER FOR PUBLIC
REPRESENTATION
5 Ferry Street #314
Easthampton, MA 01027
Phone: (413) 586-6024
sschwartz@cpr-ma.org

megans@bazelon.org

Respectfully submitted,

#### /s/ Aaron M. Panner

Aaron M. Panner
Rachel T. Anderson
Tiberius T. Davis\*
Nataliia Gillespie
KELLOGG, HANSEN, TODD,
FIGEL & FREDERICK, P.L.L.C.
1615 M Street, N.W., Suite 400
Washington, D.C. 20036
Phone: (202) 326-7900
apanner@kellogghansen.com
randerson@kellogghansen.com
tdavis@kellogghansen.com
ngillespie@kellogghansen.com

Martha Jane Perkins
NATIONAL HEALTH LAW
PROGRAM
1512 East Franklin Street
Suite 110
Chapel Hill, NC 20514
Phone: (919) 968-6308
perkins@healthlaw.org

<sup>\*</sup> Not admitted in the District of Columbia. Practice supervised by members of the firm.

#### CERTIFICATE OF COMPLIANCE

This brief complies with the type-volume limits of Federal Rule of Appellate Procedure 29(a)(5) because, according to the word-processing system used to prepare it (Microsoft Word 2016), it contains 5,277 words, excluding the portions of the brief exempted by Federal Rule of Appellate Procedure 32(f).

I further certify that this brief complies with the typeface and type style requirements of Federal Rule of Appellate Procedure 32(a)(5) and (a)(6) because it has been prepared using Microsoft Word 2016 in a proportionally spaced typeface (Century Schoolbook, 14 point).

/s/ Aaron M. Panner
Aaron M. Panner