# UNITED STATES DISTRICT COURT SOUTHERN DISTRICT OF INDIANA INDIANAPOLIS DIVISION

)	
)	
Case No. 1:24-cv-00833-TWP-TAB	
)	
	)
	)

# **ORDER ON PLAINTIFFS' MOTION FOR PRELIMINARY INJUNCTION**

The complex circumstances that led to this action surround Plaintiffs' claims that without a preliminary injunction, on September 1, 2024, the ability of two single parents to continue providing care to their medically fragile children with rare unpredictable conditions that necessitate the constant presence of someone specifically trained to attend to their needs, may end. This matter is before the Court on a Motion for Preliminary Injunction filed pursuant to Federal Rule of Civil Procedure 65 by Plaintiffs Indiana Protection and Advocacy Services Commission ("IPAS"), E.R., and G.S. (together, "Individual Plaintiffs") (Filing No. 9). IPAS and the Individual Plaintiffs initiated this action against Defendants Indiana Family and Social Services Administration ("FSSA"), Secretary of the FSSA, and its Director of the Division of Disability and Rehabilitative Services (collectively, "FSSA"), alleging violation of the Integration Mandate of the Americans with Disabilities Act of 1990 ("ADA"), the Rehabilitation Act of 1973, and federal

Medicaid Law. For the reasons that follow, the Court determines that IPAS has a strong likelihood of success on its claims, has no adequate remedy at law, and faces irreparable harm if FSSA is not enjoined. Accordingly, a modified injunctive relief is **granted**.

## I. <u>BACKGROUND</u>

As the Seventh Circuit has noted, "[n]o one would accuse the Medicaid program of simplicity." *Steimel v. Wernert*, 823 F.3d 902, 906 (7th Cir. 2016). This case revolves around various intricacies of federal Medicaid law and an array of services that medically complex children enrolled in Indiana might be able to receive. Medicaid is a cooperative federal-state program, codified at 42 U.S.C. § 1396, *et seq.*, through which the federal government provides financial assistance to states so that they may furnish medical care to needy individuals (Filing No. 1 ¶ 14). State participation in the Medicaid program is voluntary. However, states that choose to participate in the Medicaid program must, as a condition of receiving federal funds, comply with the requirements and standards established by federal law. *Id.* ¶ 15. In Indiana, the Medicaid program ("State Plan") is administered by FSSA. *Id.* ¶ 25.

The State Plan covers traditional Medicaid services, as well as several home- and community-based Medicaid waiver programs (Filing No. 38-1 ¶ 6). The Centers for Medicare & Medicaid Services ("Medicaid Centers") reviews and approves the State Plan for compliance with federal Medicaid laws and regulations. *Id.* ¶ 7. Individuals are eligible for traditional Medicaid services if they are Medicaid eligible. *Id.* ¶ 12. Medicaid eligibility is determined by the individual's disability status and family income. *Id.* Individuals are eligible for waiver programs if they are Medicaid eligible and functionally eligible. The individual meets functional eligibility if he or she requires significant direct assistance on a daily basis due to substantial or complex medical conditions. *Id.* For years, FSSA has provided multiple services and programs to assist those who are Medicaid and functionally eligible.

## A. <u>Services Provided under Indiana's Medicaid Program</u>

The State Plan covers a wide range of services. Relevant to this case, the State Plan covers services through home- and community-based waiver programs and services through the traditional Medicaid program.

### 1. Waiver Programs

Pursuant to 42 U.S.C. § 1396n(c)(1), the Secretary of the U.S. Department of Health and Human Services may waive certain requirements of federal Medicaid law for states that include as "medical assistance" home- and community-based services that are provided to individuals "with respect to whom there has been a determination that but for the provision of such services the individuals would require the level of care provided in a hospital or a nursing facility or intermediate care facility for the [intellectually disabled]." (Filing No. 1 ¶ 16.) Home- and community-based services available under a waiver may include, *inter alia*, case management services, personal care services, and any other services requested by a state and approved by the federal government "as cost effective and necessary to avoid institutionalization." *Id.* ¶ 20.

For an individual who meets the nursing facility level of care and is a Medicaid beneficiary, FSSA will enroll the individual in the waiver program, subject to waiver capacity (<u>Filing No. 38-1</u>¶13). Until July 1, 2024, Indiana provided waiver services to eligible enrollees through its Aged and Disabled Medicaid Waiver Program.

#### a. The Aged and Disabled Medicaid Waiver Program

The Aged and Disabled Medicaid Waiver Program ("A&D Waiver") provides home- and community-based services to persons who it has determined meet "nursing facility level of care." (Filing No. 1 ¶ 27.) Pursuant to the terms of the A&D Waiver, the only requirements of federal Medicaid law that are waived for that program are the requirements of 42 U.S.C. § 1396(a)(10)(B) (related to comparability). *Id.* ¶ 29. Through the A&D Waiver, enrollees may receive specific

types of services that are intended to ensure that their needs are met and that they are able to reside safely and securely in the community. *Id.* ¶ 30. As relevant to this case, enrollees in the A&D Waiver may receive attendant care services ("ATTC") or structured family caregiving ("SFC"). Both ATTC and SFC constitute "personal care services" under 42 U.S.C. § 1396d(a)(24). *Id.* ¶ 33.

ATTC is designed to provide direct, hands-on care to participants to ensure that their functional needs are met and to assist them with their activities of daily living. *Id.* ¶ 34. + These services also may be utilized to provide the care and supervision necessary to ensure the safety of participants who require constant or near constant care and supervision. *Id.* There is no "cap" on the amount of ATTC that an individual enrolled in the A&D Waiver may receive so long as all services are medically necessary. *Id.* ¶ 35. ATTC is not designed to be utilized as a substitute for medical care that should be provided by a skilled professional, such as a nurse or physician. *Id.* ¶ 34.

SFC is "a caregiving arrangement in which a participant lives with a principal caregiver who provides daily care and support to the participant based on the participant's daily care needs." *Id.* ¶ 36. Providers of structured family caregiving services may provide services related to the waiver recipient's activities of daily living as well as medication oversight and other appropriate supports for which the caregiver has received training and as described in the waiver recipient's service plan. *Id.* Like ATTC, SFC is not to be provided "to medically unstable or medically complex participants as a substitute for care provided by a registered nurse, licensed practical nurse, licensed nurse, or other health professional." *Id.* 

Pursuant to the terms of the A&D Waiver, ATTC and SFC may not be provided by "Legally Responsible Individuals". *Id.* ¶ 37. A Legally Responsible Individual is any person who has a duty under state law to care for another person and typically includes the parents or guardians of a

minor child and the spouse of an adult recipient. *Id.* However, despite the terms of the formal A&D Waiver, FSSA has long allowed parents, guardians, or other Legally Responsible Individuals to provide ATTC and SFC. *Id.* ¶ 38. For some waiver recipients and their families this is a matter of choice. *Id.* ¶ 39. But for a great number of them, Legally Responsible Individuals providing ATTC and SFC has been an absolute necessity. *Id.* ¶ 40; *see id.* 41-42.

# b. The Health and Wellness Waiver, formerly the A&D Waiver

In 2023, FSSA discovered that it was facing an unanticipated increase in forecasted Medicaid expenditures and a budget variance of approximately \$986 million. *Id.* ¶ 53. This discovery caused an internal review of multiple programs and after the review, FSSA determined that the variance, in significant part, was due to ATTC provided by Legally Responsible Individuals (*see Filing No. 38-1* ¶ 17). As a result of the discovered variance, FSSA implemented mitigation strategies beginning in January 2024 (*Filing No. 38-2* ¶ 18).

On January 17, 2024, FSSA issued a letter explaining its Medicaid forecast mitigation strategies (Filing No. 38-1 ¶ 19). One prominent mitigation decision was that under the proposed Health and Wellness Waiver ("H&W Waiver"), a Legally Responsible Individual would not be permitted to provide ATTC but could now provide SFC without violating Medicaid regulations. *Id.* ¶ 25. On June 4, 2024, Medicaid Centers approved the H&W Waiver. *Id.* ¶ 24. Families utilizing Legally Responsible Individual-provided ATTC under the A&D Waiver would have to transition to a non-Legally Responsible Individual ATTC provider or transition to the service of SFC on or before July 1, 2024. *Id.* ¶ 19. This change was implemented to address the budget variance and to ensure that FSSA's practices aligned with approved definitions. *Id.* ¶ 20. Stated differently, the service definitions in the A&D Waiver did not allow Legally Responsible Individuals to provide ATTC or SFC. FSSA has the discretion to define "personal care services" differently to allow Legally Responsible Individuals to serve as paid providers of ATTC or SFC,

(Filing No. 28-4 at 60, 133, 144), but has not because they would have to limit the number of hours Legally Responsible Individuals and non-Legally Responsible Individuals could provide these services or introduce the inclusion of a fiscally sustainable definition of "extraordinary care." (Filing No. 38-1 ¶ 26.)

The H&W Waiver includes reimbursement rates for all services offered in the waiver program. *Id.* ¶ 30. FSSA reimburses ATTC at a rate of \$34.36 an hour; SFC is reimbursed at a rate of between \$77.54 and \$133.44 a day, depending on the assessed level of need (Filing No. 1 ¶ 44). However, because individuals who provide ATTC or SFC are typically employed by private companies enrolled as providers in the Medicaid program, these rates are paid to the home care agency that employs the direct caretaker, and the agency pays a portion of that to the caretaker (Filing No. 1 ¶ 45; Filing No. 38-1 ¶ 30). FSSA estimates that at most 60% of the hourly rate for ATTC (or \$20.62) will be provided to the individual caregiver, and that between 65% and 70% of the daily rate for SFC (or between \$50.40 and \$93.41) will be provided to the individual caregiver (Filing No. 1 ¶ 45). The precise compensation to be provided to caregivers, however, is determined by the private companies that employ these individuals, and the actual compensation received by individual providers may be and frequently is less than FSSA's estimates. *Id*.

On July 1, 2024, the A&D Waiver was officially replaced by the Pathways Waiver<sup>2</sup> and the H&W Waiver. *Id.* ¶¶ 10, 24. The H&W Waiver covers eligible beneficiaries who are aged 59 and under, and the Division of Disability and Rehabilitative Services administers the program (Filing No. 38-1 ¶ 10). To facilitate the transition from the A&D Waiver to the H&W Waiver, FSSA

<sup>&</sup>lt;sup>1</sup> Recipients of SFC are assigned one of three "service levels," which is determined for most enrollees through what is referenced in the formal H&W Waiver document as the AFC/SFC LOS assessment score (<u>Filing No. 28-2 at – [31</u>:14-25]). Until recipients may be properly assessed in this manner, their service level is determined by the number of ATTC hours they are approved for each week (*see Filing No. 28-3 at 36*).

<sup>&</sup>lt;sup>2</sup> The Pathways Waiver covers eligible beneficiaries who are aged 60 and over (see <u>Filing No. 38-1</u> ¶ 10). The individual plaintiffs are six and ten. Therefore, this waiver program warrants no further discussion.

requested that care managers convene planning discussions with waiver enrollees and submit a service plan update in which enrollees indicate if they will receive ATTC from a non-Legally Responsible Individual or transition to SFC, or another service option. *Id.* ¶ 31. As of July 1, 2024, FSSA had received transition service plan updates for most pediatric waiver recipients. *Id.* ¶ 32. More than 68% of the pediatric waiver recipients who submitted transition service plans have transitioned to SFC and the remaining enrollees are receiving ATTC from a non-Legally Responsible Individual or have pursued other waiver and State Plan services (such as home health only, or skilled respite nursing only). *Id.* 

## 2. Other Traditional Medicaid Programs

Other State Plan services suggested to "fill the gap" for waiver recipients who were previously receiving ATTC or SFC from Legally Responsible Individuals include home health services, "home and community assistance," ("HCA") and "adult day services." (Filing No. 28-1 at 13 [48:1-20]). Of these, only home health services provided through the traditional Medicaid program are relevant to this case.<sup>3</sup> Home health services may take the form of either skilled nursing services or unskilled nursing services from a home health aide (Filing No. 28-1 at 14 [50:1-6]).

#### a. Skilled Nursing Services

Skilled nursing services, as ordered by a physician, must be required and provided on a daily basis, essentially seven days a week (<u>Filing No. 28-5 at 58</u>). All skilled nursing services are provided within the scope of the Indiana State Nurse Practice Act. *Id.* at 127. In order for a waiver recipient to receive skilled nursing services from a home health agency, he or she must first locate

<sup>&</sup>lt;sup>3</sup> Under the H&W Waiver, HCA services provide instrumental activities of daily living such as cleaning, dusting, and removing the trash (*see* Filing No. 28-5 at 87). Adult day services are (1) for adults, and (2) community-based group programs designed to provide structured, social integration. *Id.* at 70. Neither HCA services of adult day services provide the one-on-one care, or skilled care, that the medically complex children in this case require.

a provider to submit a request for approval of those services to FSSA (<u>Filing No. 28-2 at 12</u> [43:19-44:1]). In its estimation, FSSA's only role is to approve or deny a request once submitted. *Id.* at 12[44:2-4].

#### b. Home Health Aide Services

Unskilled home health aide services may only be provided by an individual who has met certain training and related requirements specified in both federal and Indiana law and who has received formal certification as a home health aide (Filing No. 28-1 at 14 [51:20-23]). Under federal law this generally requires classroom and supervised practical training of at least 75 hours followed by a competency evaluation. *See* 42 C.F.R. § 484.80(a)-(c). Indiana law also imposes additional continuing education requirements. *See* Ind. Admin. Code tit. 410, r. 17-14-1(h).

## **B.** The Affected Parties

IPAS was created pursuant to federal mandate and funded through federal monies to represent, advocate for, and protect the rights and interests of individuals with disabilities. *See* Ind. Code § 12-28-1-1, et seq. While the issues presented in this case may certainly impact several Medicaid enrollees,<sup>4</sup> this case concerns, and focuses specifically on two Individual Plaintiffs – E.R. and G.S – who have been receiving ATTC from their mothers but will be left without necessary care due to FSSA's waiver changes.

## 1. E.R. and His Family

E.R. is a six-year-old boy who resides with his mother, Jessica Carter ("Carter") and his 19-year-old sister ("E.R.'s sister") (Filing No. 28-7 ¶¶ 2, 3). Carter is solely responsible for supporting E.R. financially and she is also his primary caretaker. *Id.* ¶ 2. E.R. has cri-du-chat

<sup>&</sup>lt;sup>4</sup> "FSSA received over 2,000 public comments from waiver recipients, their families, providers and their associations, and other stakeholders regarding provision of [] waiver services by [LRIs]." (<u>Filing No. 28-5 at 27</u>). Some of these persons "shared fear of institutionalization and expressed that [an LRI] is the most qualified individual to provide the service." *Id.* at 28.

syndrome, a rare genetic disorder caused by a missing section of a particular chromosome. *Id.* ¶ 3. He spent the first fifteen days of his life in the neonatal intensive care unit and when his condition deteriorated in his infancy, he was required to live in the hospital for approximately 18 months between 2019 and 2021. *Id.* As a result of his cri-du-chat syndrome, E.R. has a wide variety of medical diagnoses and symptoms. *Id.* ¶ 4. He has chronic lung disease, severe respiratory issues, and epilepsy that results in significant seizures that are not fully controlled by medication. *Id.* He is deaf in one ear and has impaired hearing in the other ear; he is blind in one eye and has impaired vision in the other; and he is non-verbal and non-ambulatory. *Id.* Even though he is six years old, developmentally he resembles a 9-month-old. *Id.* He requires close, 24/7, care and supervision and assistance with all of his activities of daily living. *Id.* 

Three aspects of E.R.'s daily care require particularly close attention: (1) E.R. routinely experiences severe seizures which must be responded to promptly and appropriately to avoid substantial, irreparable damage to E.R.; (2) E.R. is unable to consume food himself so he must be fed exclusively through a gastronomy tube ("G-tube") several times each day; and (3) E.R. has severe respiratory distress and must be closely monitored in case any emergent issues arise. *Id.* ¶ 5. Given these medical needs, E.R. must be continuously monitored and cannot be left with a caretaker who has not been trained to provide the specific medical care and supervision that he requires on a constant basis. *Id.* ¶ 6.

Carter searched for a lengthy period of time for a skilled professional – a registered nurse – to provide in-home services to E.R. Id. ¶ 8. She also placed E.R.'s name on the wait list at numerous different nursing agencies with no success. Id. ¶ 15. Most of the agencies primarily service adults and many lack the staff to provide services in rural Lawrence County. Id. Despite the fact that these nursing agencies do not have skilled staff available to provide in-home services

to E.R., one of these agencies has regularly requested approval for E.R. to receive skilled nursing services through the traditional Medicaid program. *Id.* ¶ 16. Should a skilled provider become available, E.R. could receive the services without delay. *Id.* 

Due to Carter and the State's inability to locate a skilled provider, <sup>5</sup> E.R.'s medical team spent two months teaching Carter to provide the care and supervision E.R. requires on a daily basis. *Id.* ¶ 8. The medical team also provided some training to E.R.'s sister. *Id.* ¶ 9. Specifically, Carter was trained to operate E.R.'s tracheostomy tube, ventilator, and G-tube. *Id.* ¶ 10. She was also trained to recognize and respond to the various types of seizures that E.R. experiences. *Id.* Today, Carter and E.R.'s sister are the only individuals who provide the constant care that he requires. *Id.* ¶ 19.

Until recently, Carter was approved to be reimbursed for approximately 112 hours each week to provide ATTC to E.R., and E.R.'s sister was approved to be reimbursed for approximately 56 hours each week. *Id.* ¶ 21. The income that Carter has received from providing ATTC has been her only income for several years. *Id.* ¶ 23. Now, under the H&W Waiver, Carter is no longer able to serve as E.R.'s paid provider of ATTC. *Id.* ¶ 24. Although this change took effect for other persons enrolled in the A&D Waiver beginning July 1, 2024, Carter has reached an agreement with FSSA that she may continue serving as E.R.'s paid provider of ATTC through September 1, 2024. *Id.* 

Carter has explored alternative ways to provide E.R. with the care he requires under the H&W Waiver but none of the options presented are feasible. Carter discussed with E.R.'s case manager the possibility of transitioning from ATTC to SFC. *Id.* ¶ 25. During these conversations

10

<sup>&</sup>lt;sup>5</sup> Approximately six months after E.R. was released from the hospital in 2021, FSSA was able to locate a registered nurse who was able to provide in-home care to E.R. for between twenty and thirty hours a week (<u>Filing No. 28-7</u> ¶ 14). However, this only lasted for six months because the nurse moved out of state to accept a higher paying position. *Id.* Since then, no nurse has been available to provide the services E.R. needs.

she was informed that she would likely receive a per diem rate of between \$79.00 and \$90.00 each day and that if she was reimbursed for SFC E.R.'s sister would be unable to provide ATTC services to E.R. *Id.* This restriction is because an enrollee may not receive both SFC and ATTC (Filing No. 28-1 at 9[31:19-25]). Carter transitioning from providing ATTC to SFC is unfeasible for three reasons. First, transitioning is not financially feasible because Carter's pay would go from approximately \$2,000.00 a week to \$630.00 a week (maximum) (Filing No. 28-7 ¶ 27). This amount is not enough to ensure that E.R.'s basic needs are met.<sup>6</sup> Second, transitioning would mean that E.R.'s sister would not get paid for ATTC, would have to seek outside employment, and would therefore be unable to provide the overnight ATTC services she currently provides. *Id.* ¶ 31. This would leave Carter in the impossible situation of having to care for E.R. at all times by herself. *Id.* Third, because SFC is reimbursed on a per diem basis, many home care agencies require that caretakers who provide these services work as independent contractors rather than as employees. *Id.* ¶ 32. This would mean Carter would not receive any benefits. *Id.* 

Carter also explored the possibility of becoming a home health aide to get reimbursed for care to E.R. Id. ¶ 33. She reached out to a company and received their onboarding materials so that she could familiarize herself with the requirements, but it was overwhelming. Id. The training and evaluation requirements to become a home health aide were too much for Carter to complete. Id. ¶ 40. Additionally, Carter has no desire to enter the medical profession. She simply wants to ensure the health and safety of her own child. Id.

If FSSA's prohibition on Carter providing ATTC goes into effect on September 1, 2024, she will be forced to return to work full-time outside of the home in order to afford basic necessities

<sup>&</sup>lt;sup>6</sup> Carter spends approximately \$600.00 per week transporting E.R. twice a week to and from Cincinnati Children's Hospital for appointments and \$500.00 a month additional therapy sessions that have been prescribed by his medical providers (Filing No. 28-7 ¶¶ 28, 29).

for herself and E.R. Id. ¶ 41. Because she obviously cannot leave E.R. alone in order to do so, and because there are currently no other providers willing and able to provide care and supervision to E.R., she will have no other option than to explore having E.R. institutionalized. *See id*. ¶¶ 41-43.

## 2. G.S. and His Family

G.S. is a ten-year-old boy on palliative care who resides with his mother, Heather Knight ("Knight") and his three minor siblings (Filing No. 28-8 ¶¶ 2, 12). G.S.'s father plays a minimal role in his life: he visits for a couple of hours each week but is not trained to care for him and does not provide any financial support. *Id.* G.S. suffers from a plethora of conditions. G.S. has hypoxic-ischemic encephalopathy – a type of brain damage that affects the central nervous system and that may cause neurological or developmental problems – and white matter brain loss which results in developmental and intellectual deficits and, as Knight understands it, affects his mobility. *Id.* ¶¶ 3, 4. G.S. also has Lennox-Gastaut syndrome – a severe condition characterized by repeated seizures. *Id.* ¶ 4. Amplifying G.S.'s needs, he also has a severe form of dysautonomia, a disorder that disrupts the part of the nervous system that manages body processes such as blood pressure, body temperature, breathing, digestion, heart rate, and sweating. *Id.* ¶ 5.

G.S. requires close, 24/7, care and supervision, and assistance with all of his activities of daily living. *Id.* ¶ 11. He takes approximately ten different medications daily that must be administered on a specific schedule. *Id.* ¶ 6. He is also kept constantly on an oximeter as a result of chronic lung disease and dysautonomia. *Id.* ¶ 10. An oximeter is a medical device that displays G.S.'s heart rate, blood oxygen saturation level, and other vital signs. *Id.* Because G.S. is nonverbal and quadriplegic, his medical providers have informed Knight that he should have more than one caregiver for substantial parts of each day. *Id.* ¶ 11. This is because G.S. is over four feet tall and weighs 64 pounds. *Id.* He needs complete assistance with mobility, repositioning his

body, and with transfers. *Id.* However, for the vast majority of the time, Knight does not have any assistance and performs these tasks on her own although extremely difficult and often physically painful. *Id.* 

While the complexity of G.S.'s medical needs impact every aspect of his life, three aspects of his daily care require particularly close attention. Id. ¶ 13. First, he routinely experiences seizures and Knight must closely monitor him to identify the occurrence, the type, and the severity of each seize to properly respond. Id. ¶ 13(a). Second, G.S. is unable to consume food himself so he is fed exclusively through a G-tube several times each day. Id. ¶ 13(b). Knight must administer all feedings, clean the G-tube site, and monitor the site for infection or blockage. Id. Third, G.S. has severe cardiac and respiratory issues that require constant monitoring which requires Knight to remain extremely vigilant to ensure that she notices any changes to his behavior so that she may respond accordingly. Id. ¶ 13(c). Given these medical needs, G.S. cannot be left with a caretaker who has not been trained to provide the specific medical care and supervision that he requires on a constant basis. Id. ¶ 13. Knight also limits the number of persons she allows into her home because G.S. is severely immunocompromised and is at great risk of becoming extremely sick if he is introduced to any foreign germs. Id. ¶ 14.

Beginning in 2017, G.S. was approved for and placed on the A&D Waiver. *Id.* ¶ 15. G.S. was approved to receive eighty hours each week of in-home skilled nursing services through that program although half of the hours for which he was approved were not staffed. *Id.* ¶ 16. Prior to the Covid-19 pandemic a nurse provided in-home skilled nursing services for forty hours each week. *Id.* In early 2020, however, the nurse left to accept a job in Chicago. *Id.* Knight was unable to single-handedly provide G.S. with all the care and assistance that he required once the nurse left so she placed him at a pediatric nursing home. *Id.* ¶ 17. G.S.'s placement at the nursing home was

a horrendous experience; his quality of life suffered significantly, and Knight was concerned that he may have suffered abuse or neglect at the facility. *Id.* ¶ 18. Consequently, in late 2020, Knight removed him from the nursing home. *Id.* 

In or around late 2021, Knight learned that she could serve as G.S.'s paid provider of ATTC. *Id.* ¶ 19. That same year, Knight became employed by a Medicaid home care provider specifically to serve as G.S.'s provider of ATTC, and she has served as G.S.'s only paid provider of ATTC since that time. *Id.* Presently, Knight is reimbursed approximately 84 hours each week to provide ATTC care to G.S. and a nurse provides skilled nursing services through the A&D Waiver for approximately eighteen hours each week (provided in six-hour increments). *Id.* ¶ 22. The income Knight receives from providing ATTC to G.S. represents her only income. *Id.* ¶ 27. Although the nurse provides Knight some relief to go grocery shopping or run other necessary errands, it is not close to sufficient to meet all of the needs of G.S.'s nor close to sufficient to allow Knight to obtain employment outside the home. *Id.* ¶¶ 23, 24. Other than the nurse G.S. has, Knight is not aware of any skilled providers available to ensure that G.S. receives the care and supervision that he requires without risking his health. *Id.* ¶ 25.

Knight understands that under the H&W waiver she will be no longer able to serve as G.S.'s paid provider of ATTC. *Id.* ¶ 28. Although this change took effect for other persons enrolled in the A&D Waiver beginning July 1, 2024, like Carter, Knight has reached an agreement with FSSA that will allow her to continue being a paid provider of ATTC through September 1, 2024. *Id.* 

Following FSSA's announcement of changes to the A&D Waiver, Knight explored alternative ways to provide G.S. with the care he requires under the newly formed H&W Waiver. Knight discussed with G.S.'s case manager and with her employer the possibility of transitioning from providing ATTC services to G.S. to providing SFC to him instead. *Id.* ¶ 29. During these

conversations she was informed that she would be paid at most \$90.00 a day. *Id.* Knight transitioning from providing ATTC to SFC is unfeasible for two reasons. First, transitioning is not financially feasible because Knight would go from making \$15.00 an hour, approximately \$2,675.00 every two weeks, to less than half that amount under SFC. *Id.* ¶ 30. Second, because SFC is reimbursed on a per diem basis, she would have to work as an independent contractor and would not receive any benefits. *Id.* ¶ 31. When Knight attempted to comply with FSSA's new H&W Waiver requirements, her request to change providers was denied and she was not paid for six weeks forcing her to borrow money to live and support her family. *Id.* ¶ 32.

Knight also considered becoming a home health aide for G.S. to potentially get reimbursed through the traditional Medicaid program. *Id.* ¶ 33. She registered for an online course through a provider of home health services but has had great difficulty finding time to take the course. *Id.* ¶ 35. Because she has to complete the classes after a full day of caring for G.S., she has a hard time paying attention to the class. *Id.* So far she has completed only 8 of 21 classes in the first of four parts. *Id.* ¶ 36. It is improbable that Knight could complete all the required courses and receive certification to become a home health aide prior to September 1, 2024. *Id.* 

If FSSA's prohibition on Knight providing ATTC goes into effect on September 1, 2024, she would be forced to obtain a job outside of the home to afford basic necessities for her family, leaving G.S. home alone. Id. ¶ 38. However, because G.S. needs someone to attend to his needs at all times and cannot be left alone, there would be no other option but to seek institutional placement. Id. ¶ 39.

#### II. <u>LEGAL STANDARD</u>

"A preliminary injunction is an extraordinary remedy never awarded as of right." *Winter* v. *Natural Resources Defense Council, Inc.*, 555 U.S. 7, 24 (2008). "In each case, courts must balance the competing claims of injury and must consider the effect on each party of the granting

or withholding of the requested relief." *Id.* (citation and quotation marks omitted). Granting a preliminary injunction is "an exercise of a very far-reaching power, never to be indulged in except in a case clearly demanding it." *Roland Mach. Co. v. Dresser, Inc.*, 749 F.2d 380, 389 (7th Cir. 1984) (citation and quotation marks omitted). The party seeking the injunctive relief must demonstrate that:

(1) it has a reasonable likelihood of success on the merits of its claim; (2) no adequate remedy at law exists; (3) it will suffer irreparable harm if preliminary injunctive relief is denied; (4) the irreparable harm it will suffer without preliminary injunctive relief outweighs the irreparable harm the nonmoving party will suffer if the preliminary injunction is granted; and (5) the preliminary injunction will not harm the public interest.

Platinum Home Mortg. Corp. v. Platinum Fin. Group, Inc., 149 F.3d 722, 726 (7th Cir. 1998). Courts in the Seventh Circuit employ a sliding scale approach where the greater the likelihood of success, the less harm the moving party needs to show to obtain an injunction, and vice versa. Girl Scouts of Manitou Council, Inc. v. Girl Scouts of the United States of America, Inc., 549 F.3d 1079, 1086 (7th Cir. 2008).

## III. <u>DISCUSSION</u>

At this stage of the case, the only issue before this Court is whether IPAS and the Individual Plaintiffs are entitled to the preliminary injunctive relief they seek; specifically, "enjoining [FSSA] from prohibiting or otherwise restricting these two Legally Responsible Individuals of enrollees in the [H&W Waiver]<sup>7</sup> from serving as providers of [ATTC] through that program, pending further order of the Court." (Filing No. 1 at 34). As previously stated, to obtain a preliminary injunction, IPAS must establish the following factors: (1) that it is likely to succeed on the merits of its claims;

16

<sup>&</sup>lt;sup>7</sup> IPAS specifically asks this Court to enjoin FSSA from restricting LRIs of enrollees in the *A&D Waiver* from serving as providers of ATTC. (Filing No. 1 at 34) (emphasis added). As of July 1, 2024, the A&D Waiver no longer exists and E.R. and G.S. both receive services under the newly formed H&W Waiver. Therefore, the relief IPAS seeks must fall under the H&W Waiver.

(2) that it has no adequate remedy at law; (3) that it is likely to suffer irreparable harm in the absence of preliminary relief; (4) that the balance of equities tip in its favor; and (5) issuing the injunction is in the public interest. *Platinum Home Mortg. Corp.*, 149 F.3d at 726. The first two factors are threshold determinations. "If the moving party meets these threshold requirements, the district court 'must consider the irreparable harm that the nonmoving party will suffer if preliminary relief is granted, balancing such harm against the irreparable harm the moving party will suffer if relief is denied." *Stuller, Inc. v. Steak N Shake Enterprises, Inc.*, 695 F.3d 676, 678 (7th Cir. 2012) (quoting *Ty, Inc. v. Jones Group, Inc.*, 237 F.3d 891, 895 (7th Cir. 2001)). The Court will address the threshold factors before addressing the remaining factors.

## A. Likelihood of Success on the Merits

IPAS has asserted claims under Title II of the ADA and Section 504 of the Rehabilitation Act of 1973 alleging that FSSA's changes to the A&D Waiver places children at risk of institutionalization and therefore violate the "integration mandate" and federal Medicaid law (*see Filing No. 1* ¶¶ 138, 140). IPAS has also asserted a claim under 42 U.S.C. § 1983 alleging that to the extent ATTC is deemed to be any service available under federal Medicaid law other than "personal services," the prohibition violates the "free choice of provider" provision of federal Medicaid law, 42 U.S.C. § 1396(a)(23) (*see id.* ¶ 141). The Court now considers the likelihood of IPAS' success on the merits of the claims.

## 1. The Integration Mandate

Title II of the ADA prohibits discrimination in access to public services by requiring 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,

<sup>&</sup>lt;sup>8</sup> Throughout its briefing, IPAS fails to address this claim and it is therefore waived.

or be subjected to discrimination by any such entity." 42 U.S.C. § 12132. Contained within the ADA is an "integration mandate" which requires "[a] public entity [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); see Olmstead v. L.C. ex rel Zimring, 527 U.S. 581, 597 (1999). The regulations' preamble defines "the most integrated setting appropriate to the needs of qualified individuals with disabilities" as "a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible." Steimel, 823 F.3d at 909. "Because the relevant provisions of the Rehabilitation Act and its regulations are materially identical to their ADA counterparts, courts construe and apply them in a consistent manner." Id. (internal citations omitted).

As an initial matter, the Court must determine whether the integration mandate is implicated by IPAS' claims. If the integration mandate is implicated as IPAS' contends, the Court will then determine whether it was violated. *See Olmstead*, 527 U.S. 581.

#### a. The Integration Mandate is Implicated

The Integration Mandate of the ADA is implicated where the state's policies have either (1) segregated persons with disabilities within their homes, or (2) put them in serious risk of institutionalization. *Steimel*, 823 F.3d at 914. IPAS asserts that given the Individual Plaintiffs' medical needs and functional limitations, they require constant 24/7 care and supervision (*see Filing No. 31 at 22-23*). A recent instruction from E.R.'s medical team supports this assertion: "[m]other understands and agrees to maintain [E.R.'s] health and well being [*sic*] he should only be left under the supervision of someone who has been specifically trained with his particular health conditions." (Filing No. 45-1 at 11) (*see also Filing No. 45-2* ¶ 3 (Knight stating that she has been "instructed by G.S.'s medical staff that [she] is not to leave G.S. with an untrained caregiver for *any* amount of time – day or night.") (Emphasis in original).)

Given that the Individual Plaintiffs need 24/7 care, IPAS argues they are at serious risk of institutionalization because beginning on September 1, 2024 – when the mothers are no longer allowed to be paid providers of ATTC – the services available to E.R. and G.S. are insufficient to ensure that their needs are met in the community (see Filing No. 31 at 23). SFC through the H&W Waiver is insufficient to ensure the Individual Plaintiffs' needs are met because the reimbursement rate of \$90.00 per day is inadequate to support a family, so the mothers would have to obtain outside employment leaving E.R. and G.S. without the care that they require. Similarly, home health aide services are insufficient because the services may only be provided on a part-time basis, and they must be provided by someone who has met all training, evaluation, and certification requirements. Neither Carter nor Knight are certified home health aides, and they cannot become certified home health aides because they currently spend most of their time caring for their medically complex children. The last option, in-home skilled nursing assistance, is insufficient because to date, the assistance has not been made available to the Individual Plaintiffs in the capacity that they require given their complex needs.

FSSA contends that the Individual Plaintiffs are not at serious risk of being institutionalized because their assertions - that (1) E.R. and G.S. need 24/7 care and supervision and (2) absent their mothers providing ATTC they will be unable to receive sufficient care – are conclusory and incorrect (see Filing No. 37 at 16). FSSA's position that the Individual Plaintiffs do not need 24/7 care and supervision is contradicted by the eligibility screen completed by the State.<sup>9</sup>

S. Maria Finnell, M.D. ("Dr. Finnell"), FSSA's Chief Medical Officer, – and by extension, FSSA – appears to conflate "care" with "services" and "literal watching." Dr. Finnell states that

<sup>&</sup>lt;sup>9</sup> (See Filing No. 39-2 at 3 ("[E.R.] requires 24 hours a day supervision and/or direct assistance to maintain safety"); Filing No. 45-5 at 2 ("[G.S.] requires 24 hours a day supervision and/or direct assistance to maintain safety.").)

neither E.R. nor G.S. require services or monitoring 24 hours a day, 7 days a week (*see Filing No.* 39-1 ¶ 8), but agrees that neither should be left with someone unfamiliar with their needs (*see id.* ¶¶ 24, 32). Dr. Finnell's opinion is consistent with IPAS' assertion that E.R. and G.S. require 24/7 care. <sup>10</sup>

Next, FSSA argues that the Individual Plaintiffs have several ways to structure their care to prevent institutionalization. FSSA points out that prior to the mothers becoming paid providers of ATTC, the Individual Plaintiffs lived at home and were not institutionalized (see Filing No. 37 at 17). During this time period, E.R.'s family was forced to live with Carter's parents (Filing No. 45-1 ¶ 19) and G.S., his three siblings, and Knight lived with a G.S.'s father who was emotionally abusive to Knight and her children (Filing No. 45-2 ¶ 22). Neither prior living situation is available to the Individual Plaintiffs today (see Filing No. 45-1 ¶ 20; Filing No. ¶ 23). Moreover, during this time period, Carter and Knight were not receiving any income; E.R.'s family was supported through GoFundMe donations (Filing No. 45-1 ¶ 19) and G.S.'s family was supported by G.S.'s father (Filing No. 45-2 ¶ 23). No family can live and provide for their children, let alone medically complex children, without an income. See Waskul v. Washtenaw Cnty. Cmty. Mental Health, 979 F.3d 426, 462 (6th Cir. 2020) (finding that a waiver recipient would be "at serious risk of institutionalization if his guardian [was] unable to continue caring for him due to [their] dire financial situation" brought about by the fact that they were "unable to work during the time [they] has to stay home with [the waiver recipient]").

FSSA also argues that there are an array of services the Individual Plaintiffs could utilize that make institutionalization very unlikely but they fail to use them (*see Filing No. 37 at 17-20*). First, FSSA highlights the fact that the parents fail to utilize all of the skilled-nursing services the

<sup>&</sup>lt;sup>10</sup> "Care" means to have "responsibility for or attention to health, well-being, and safety." *Care*, MERIAM-WEBSTER (11th ed. 2003). At all times, whichever persons are left with the Individual Plaintiffs must be able to provide care.

Individual Plaintiffs have been approved for. All this fact highlights is that despite Medicaid approving reimbursement for skilled services, they have not provided the staff needed to provide this care (*see Filing No. 28-7* ¶ 17; Filing No. 28-8 ¶ 26). Next, FSSA contends that if the Individual Plaintiffs utilized services available through the public school system, they would not be at risk for institutionalization. The Individual Plaintiffs have attempted to utilize school services and although those services are available in theory, they are not available in actuality. The public school system has stated that neither E.R. nor G.S. may attend school unless they have a one-on-one nurse (*see Filing No. 45-1* ¶ 23). 11

Looking at the facts presented by IPAS and the history of services FSSA has *actually* provided to the Individual Plaintiffs, as a result of FSSA's changes to the A&D Waiver, E.R. would lose 112 hours a week of services from a trained provider, and G.R. would lose 84 hours a week of services. <sup>12</sup> The loss of these services is sufficient to show that the Individual Plaintiffs are at serious risk for institutionalization.

#### b. Violation of the Integration Mandate

In *Olmstead*, the United States Supreme Court determined that discrimination under Title II of the ADA includes "unnecessary segregation" and "[u]njustified isolation" of people with disabilities. 527 U.S. at 582. Unjustified isolation of people with disabilities is a form of discrimination because it "perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life" and "severely diminishes everyday life"

<sup>12</sup> FSSA's primary argument, that the Individual Plaintiffs are not at serious risk for institutionalization, centers around a combination of services that *could* meet the Individual Plaintiffs needs' *if* received. However, the services FSSA suggests have not been provided in the past and FSSA submits no evidence that the services *will* be provided absent a preliminary injunction being granted.

<sup>&</sup>lt;sup>11</sup> At oral argument, counsel for IPAS stated that before this year, E.R. was not allowed to attend school because he was on a ventilator and in anticipation of this upcoming year, school staff has informed Carter that E.R. may not attend unless she provides his own nurse.

activities of individuals, including family relations, social contacts ... educational independence, educational advancement, and cultural enrichment." *Id.* at 601. A state violates the ADA's integration mandate to administer services in the most integrated setting appropriate to the needs of qualified individuals with disabilities if through its planning, service system design, funding choices, or service implementation practices, it promotes or relies upon the segregation of individuals with disabilities in private facilities or programs. *Vaughn v. Walthall*, 968 F.3d 814, 819 (7th Cir. 2020).

Olmstead set out a test for determining whether the integration mandate has been violated. 527 U.S. at 607. Under the test,

States are required to provide community-based treatment for persons with mental disabilities when [1] the State's treatment professionals determine that such placement is appropriate, [2] the affected persons do not oppose such treatment, 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.* The first two prongs of the *Olmstead* test are undisputed – FSSA has determined that community-based services are appropriate for the Individual Plaintiffs and the Individual Plaintiffs do not oppose these services. Therefore, only the third prong is at issue.

FSSA contends that IPAS' proposed modifications cannot be reasonably accommodated when taking into account the resources available to the State and raises a "fundamental alteration" defense. ADA regulations provide that "[a] public entity shall make reasonable accommodations in policies, practices, or procedures when modifications are necessary to avoid discrimination on the basis of disability, *unless* the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity. *Olmstead*, 527 U.S. at 607 (citing 28 C.F.R. § 35.130(b)(7) (emphasis added)). "The evaluation of whether a change would fundamentally alter the nature of a program should be holistic." *Steimel*, 823 F.3d at 915.

"A court must therefore take care to consider the cost of a plaintiff's care not in isolation, but in the context of the care it must provide to all individuals with disabilities comparable to those of the plaintiff." *Radaszewski ex rel. Radaszewski v. Maram*, 383 F.3d 599, 614 (7th Cir. 2004).

FSSA argues that enjoining their July 1, 2024, changes and permitting Legally Responsible Individuals to be paid providers of ATTC would have a potentially debilitating effect on the budget for the H&W Waiver, threatening the waiver's existence, and jeopardizing the Indiana Medicaid budget as a whole (see Filing No. 37 at 22-23; see also Filing No. 38-3 ¶ 12 (summarizing likely consequences)). However, these budgetary concerns conflate the issues in this case. This case is not about how many services an enrollee may receive, it is about who may provide those services to the enrollee. Should both mothers find a non-Legally Responsible Individual to provide ATTC services to the Individual Plaintiffs, as FSSA has suggested in their transition plan, the cost to the State would be identical to what it is now (see Filing No. 28-3 at 36, 46, 48). Alternatively, if the mothers are unable to find a non-Legally Responsible Individual provider of ATTC and rely solely on the in-home nursing services they have been approved for, the cost to the State would be almost identical to the cost of ATTC.<sup>13</sup> Moreover, if the State is unable to find a nurse to provide services and the Individual Plaintiffs need to be institutionalized, that would certainly come at a greater expense to the State. See A.H.R. v. Washington State Health Care Authority, 469 F. Supp. 3d 1018, 1048 (W.D. Wash. 2016) (noting that paying for services in a hospital is a more costly alternative than paying for the in-home nursing care plaintiffs sought).

\_

<sup>&</sup>lt;sup>13</sup> The Individual Plaintiffs have been approved for a total of 120 hours of in-home skilled nursing care (<u>Filing No. 28-8</u> ¶ 16; <u>Filing No. 28-7</u> ¶ 16). Assuming the Individual Plaintiffs receive the care they have been approved for, five days out of the week, the cost to the State would be \$6,379.80 [{120 hours x \$50.29 (home nursing reimbursement rate)} + {10 days x \$34.50 (overheard cost per day)}]. (*See Filing No. 28-3 at 87.*)

Courts have repeatedly rejected fundamental-alteration defenses that rest simply on a different apportionment of services. *See Steimel*, 823 F.3d at 916; *Townsend v. Quasim*, 328 F.3d 511, 517 (9th Cir. 2003) (issue concerning "what location [] services [would] be provided"); *B.N. ex rel. A.N. v. Murphy*, No. 3:09-CV-199-TLS, 2011 WL 5838976, at \*9 (N.D. Ind. Nov. 16, 2011) (attempting to "make sure the proper funding services were used"). FSSA's policy changes simply shift funding from one line of the State's budget (ATTC) to another (in-home nursing and traditional Medicaid services). FSSA's financial concerns are insufficient to establish a fundamental alteration. <sup>14</sup>

FSSA also argues requiring them to pay Legally Responsible Individuals to provide ATTC would be a fundamental alteration because they would have to create a new service that does not exist (*see Filing No. 37 at 23-25*). It is undisputed that IPAS' proposed solution is not permitted under the H&W Waiver (*see Filing No. 28-5 at 75-76*). Under federal regulations, family members are prohibited from providing "personal care services," such as those provided under ATTC, unless a state elects to make payment for such services. 42 C.F.R. § 440.167; *cf.* Medicaid Centers Technical Guidance, (available at **Error! Hyperlink reference not valid.**) ("[t]hrough an HCBS waiver, a state may elect to make payment for personal care or similar services that are rendered by [Legally Responsible Individuals] when such services are deemed extraordinary care so long as the state specifies satisfactory criteria for authorizing such payments.").

FSSA cannot rely on its decision to limit the terms of who could provide ATTC under the H&W Waiver to demonstrate a fundamental alteration. In *Steimel*, the Seventh Circuit addressed

<sup>&</sup>lt;sup>14</sup> Although our analysis highlights the cost to the State when providing care to the individual plaintiffs, the analysis applies equally when we look at the cost to the State in the context of the care it must provide to all individuals with disabilities comparable to those of the Individual Plaintiffs. If all waiver recipients needed to seek in-home skilled nursing services or institutionalization as a result of FSSA's changes to the A&D Waiver, costs would increase under those budget line items in a manner comparable to the increase seen under ATTC. This contradicts FSSA's "budget neutrality" argument (*see Filing No. 37 at 23; Filing No. 38-4* ¶¶ 12-14).

this very argument. *See* 823 F.3d at 916. In 2011, the State enacted a policy change to the A&D Waiver, after realizing it had not been adhering to A&D Waiver rules it created, which made several persons ineligible for care. *Id.* at 906. When plaintiffs sought changes to the waiver program, arguing the changes violated the integration mandate, the State asserted a fundamental alteration defense. *Id.* at 916. The Seventh Circuit rejected this defense saying:

[T]he state's logic is circular. After all, the state creates the waiver programs, and therefore those programs' eligibility criteria. If the state's own criteria could prevent the enforcement of the integration mandate, the mandate would be meaningless.... [the state] cannot avoid the integration mandate by binding its hands in its own red tape.

*Id.* FSSA explicitly acknowledges that it has the authority under federal law to allow Legally Responsible Individuals to serve as paid providers are ATTC (*see* Filing No. 38-1 ¶ 26). Accordingly, this argument fails to establish a fundamental alteration defense as well. <sup>15</sup>

Here, there is substantial evidence that the Individual Plaintiffs would be forced into institutionalized care unless their parents are able to secure ATTC reimbursement, or alternatively, FSSA ensures the provision of home nursing services. *See supra* § I.B. FSSA has failed to establish a fundamental alteration defense. IPAS is likely to succeed on the merits of their integration mandate claims.

#### 2. Medicaid Act

Under 42 U.S.C. § 1396(a)(10)(A), "[a] state plan for medical assistance must ... provide for making medical assistance available [for described services] to" all eligible individuals. Previously, where the Medicaid Act referred to "medical assistance," it specified that states were responsible for providing "payment of part or all of the cost of services." 42 U.S.C. § 1396d(a)

25

<sup>&</sup>lt;sup>15</sup> FSSA also attempts to argue that the Individual Plaintiffs are seeking a new service – one that allows providers of ATTC to be paid for skilled services (see <u>Filing No. 37 at 25</u>). IPAS clarifies that they are not seeking to be paid for skilled services (*see Filing No. 47-1 at 16*). Therefore, this argument warrants no further discussion.

(2009). The Seventh Circuit interpreted this language narrowly, calling Medicaid "a payment scheme, not a scheme for state-provided medical assistance." *See Bruggeman ex rel. Bruggeman v. Blagojevich*, 324 F.3d 906, 910 (7th Cir. 2003). But as part of the Patient Protection and Affordable Care Act, Congress amended the definition of "medical assistance" in the Medicaid Act to clarify that a participating state is "required to provide (or ensure the provision of) services, not merely pay for them." *See O.B. v. Norwood*, 838 F.3d 837, 843 (7th Cir. 2016) (citing *A.H.R.*, 469 F. Supp. 3d at 1040 (internal quotation marks omitted). The Medicaid Act also requires that medical assistance provided through a state's Medicaid program "be furnished with reasonable promptness to all eligible individuals." 42 U.S.C. §1396a(a)(8). Federal regulations reiterate that this assistance be furnished "promptly to recipients without any delay caused by the agency's administrative procedures." 42 C.F.R. § 435.930(a).

Of particular importance to this case, the state must provide all persons in the state who are under the age of 21 early and periodic screening, diagnostic, and treatment ("EPSDT") services. *See* 42 U.S.C. § 1396a(a)(43). These services are defined to include all "necessary health care, diagnostic services, treatment, and other measures ... to correct or ameliorate defects and physical and mental illnesses and conditions ... whether or not such services are covered under the State plan." 42 U.S.C. § 1396(d)(r)(5). Therefore, service categories that must be covered under the EPSDT provision include "home health care services," which includes in-home nursing care. *See* 42 U.S.C. § 1396d(a)(7); 42 C.F.R. § 440.70(b).

IPAS alleges that FSSA has violated the Medicaid Act by failing to ensure the provision of in-home nursing services to the Individual Plaintiffs (Filing No. 31 at 29-30). IPAS analogizes this case to *O.B.* In *O.B.*, the lead plaintiff was a medically complex child who had been approved by Illinois' Medicaid agency to receive in-home nursing care although the state "left it to the

parents to find the nurses." *Id.* at 839-40. In affirming a preliminary injunction that required the state to "take immediate and affirmative steps to arrange directly or through referral ... in-home shift nursing services," the Seventh Circuit clarified that a state must ensure the provision of the "care and services" needed by the patient *and* the "payment of part or all of their cost." *Id.* at 842-43. Although FSSA has approved the Individual Plaintiffs for in-home skilled nursing and have agreed to pay for those services if obtained, E.R. and G.S. have been without nursing care for years.

Despite FSSA failing to provide nursing care like the state in *O.B.*, they contend that case is distinguishable because the Seventh Circuit's ruling was, in part, based on its inability to determine from the "sparse record" facts critical to the state's argument. *See* 838 F.3d at 841-42; Filing No. 37 at 30. FSSA argues the facts here are clear – they made a list of providers available to enrollees, they utilize care managers to assist with locating providers, and they have held multiple meetings to assist families with the transition from the A&D Waiver to the H&W Waiver without interruption of services – and the evidence demonstrates that they have complied with their Medicaid obligations (Filing No. 37 at 32). FSSA also argues that if the Individual Plaintiffs have been unable to obtain the skilled nursing care they require, it is because of factors entirely outside of their control, such as the nursing shortage in Indiana (*see id.*).

Whether or not FSSA has "made available" medical assistance to the Individual Plaintiffs in this case is a close call. The Court certainly recognizes that FSSA has taken more steps than those taken in *O.B.* However, the Court is not convinced that the steps taken are enough to satisfy Medicaid's "availability" and "reasonable promptness" provisions. FSSA has informed the Court of the steps it has taken to instruct *parents* on how to recruit nurses, but it has not offered any evidence demonstrating how *it* is actively recruiting nurses (*see* Filing No. 28-1 at 19[73:2-23]).

In fact, it appears that most of the "steps" FSSA took were directed at transitioning families from ATTC to SFC (*see id.* ¶¶ 22, 31; Filing No. 28-3 at 36). The Court acknowledges that the nursing shortage in Indiana has likely exasperated the difficulty in finding providers who could ensure the medical assistance the Individual Plaintiffs need. The Court does not fault FSSA for this shortage. Nevertheless, the Individual Plaintiffs are still left without the medical assistance required to avoid institutionalization as a result of amendments FSSA chose to make. Therefore, the Court concludes that IPAS is likely to succeed on its Medicaid claim as well.

# B. <u>Irreparable Harm</u>

Finding that IPAS is likely to succeed on the merits, next the Court considers the irreparable harm that the nonmoving party will suffer if preliminary relief is granted, balancing such harm against the irreparable harm the moving party will suffer if relief is denied. *Grace Schools v. Burwell*, 801 F.3d 788, 795 (7th Cir. 2015).

"In cases alleging that a state law violates the federal Medicaid statue and requesting injunctive relief, irreparable harm nearly always follows a finding of success on the merits." *Smith v. Benson*, 703 F. Supp. 2d 1262, 1278 (S.D. Fla. 2010) (citing cases). Numerous federal courts have recognized that the reduction or elimination of public medical benefits irreparably harms the participants in the programs being cut. Therefore, "Medi[caid] recipients may demonstrate a risk of irreparable injury by showing that enforcement of a proposed rule 'may deny them needed medical care." *Indep. Living Ctr. of S. Cal., Inc. v. Maxwell-Jolly*, 572 F.3d 644, 658 (9th Cir. 2009) (citation omitted), *vacated and remanded on other grounds sub nom. Douglas v. Indep. Living Ctr. of S. California, Inc.*, 565 U.S. 606 (2012); *see also Bontrager v. Indiana Fam. & Soc. Servs. Admin.*, 697 F.3d 604, 611 (7th Cir. 2012) (finding a risk of irreparable injury when plaintiffs would be denied medically necessary care); *Beltran v. Myers*, 677 F.2d 1317, 1322 (9th Cir. 1982) (holding that the possibility of plaintiffs being denied Medicaid benefits sufficient to establish

irreparable harm); *Fishman v. Paolucci*, 628 F. App'x 797, 801 (2d Cir. 2015) ("A lack of medical services is exactly the sort of irreparable harm that preliminary injunctions are designed to address.").

IPAS argues that absent the provision of ATTC reimbursement, the Individual Plaintiffs are at risk of institutionalization or suffering significant, potential mortal, harm (Filing No. 31 at 32). IPAS has submitted substantial evidence that the Individual Plaintiffs are medically complex children that require the constant presence of caregivers trained to provide skilled assistance (*see* Filing No. 28-7; Filing No. 28-8). IPAS has also submitted substantial evidence demonstrating that without the parents being paid providers of ATTC, they will be forced to return to work, leaving the Individual Plaintiffs without the necessary medical care (Filing No. 28-7 at ¶ 41; Filing No. 28-8 at ¶ 30, 38-39). *See Steimel*, 823 F.3d at 913 ("[t]he plaintiffs in our case have provided evidence that they need constant supervision and, despite their best efforts, the services provided under the [state's] waiver have proved inadequate to prevent life-threatening gaps in care."). Because the mothers obviously cannot leave the Individual Plaintiffs unsupervised, they would be forced to seek institutional placement (Filing No. 28-7 ¶ 41, 43; Filing No. 28-8 ¶ 39).

FSSA contends that the "[Individual Plaintiffs] are not at serious risk of institutionalization and their needs are already being met or may be met by a different combination of services available to them." (Filing No. 37 at 34.) At oral argument, FSSA asserted that Dr. Finnell's statements are in contrast to the Mothers' affidavits, where at least one of them says a trained caregiver has to be awake with their child at all times. FSSA pointed out that Plaintiffs carry the burden of persuasion by a clear showing, and where there are "two equally credible versions of the facts the court should be highly cautions in granting an injunction without the benefit of a full trial" and in such a situation, the district court "must pay particular attention to whether the movant has

satisfied threshold requirements of irreparable harm." *Lawson Products, Inc. v. Avnet, Inc.* 782 F.2d 1429, 1440 (7<sup>th</sup> Circuit 1986). The Court concludes that Plaintiffs have met their burden.

First, FSSA's position ignores a fundamental point that IPAS has devoted over fifty pages of briefing to the facts that the Individual Plaintiffs' needs are being met, in large part, because of their parents and without their parents being paid providers of ATTC they can no longer provide such care. Second, FSSA's present assertion that the Individual Plaintiffs' needs may be met by a different combination of services contradicts the undisputed evidence and arguments presented at oral argument. It is not enough for the Individual Plaintiffs' needs to be met *eventually*; they would need to be met immediately following this Court's ruling. It is undisputed that there is a nurse shortage in Indiana and that nurses are unable to provide skill nursing services for the number of hours G.S. and E.R. are approved for (*see* Filing No. 37 at 32; Filing No. 38-9; Filing No. 38-23; Filing No. 28-8 ¶¶ 22, 25).

FSSA also argues IPAS has undermined its claims that they face irreparable harm by delaying bringing this lawsuit (Filing No. 37 at 34). FSSA cites *Tranchita v. Callahan*, 511 F. Supp. 3d 850, 882 (N.D. III. 2021) to support its position. However, *Tranchita* is inapposite. In *Tranchita*, the plaintiff sought a preliminary injunction in federal court 18 months after her coyote was seized, and in harm's way, alleging that the coyote would likely die if not returned home. 511 F. Supp. At 882. Here, IPAS became aware of the anticipated July 1, 2024 changes to the A&D Waiver in January 2024. IPAS then initiated this action in May. Certainly, a five-month delay in filing a case involving complex issues surrounding the intricacies of Medicaid is not comparable to the 18-month delay in *Tranchita*. Moreover, it is whether the defendant has been "lulled into a false sense of security or had acted in reliance on the plaintiff's delay" that influences whether a plaintiff's delay in moving for a preliminary injunction is acceptable or not. *See Ty, Inc.*, 237 F.3d

at 903. FSSA has presented no affirmative evidence that IPAS' minimal delay in seeking a preliminary injunction caused them to be lulled into a false sense of security or that they relied on IPAS' delay.

The Court is not persuaded by FSSA's arguments. In determining whether the Individual Plaintiffs would be harmed absent an injunction, this Court will not speculate as to whether necessary services, that are not presently available, will become available should the Court deny the request for injunction. The Individual Plaintiffs have complex needs and both parties agree that someone qualified to perform skilled services needs to be present for *at least* thirty to forty hours per week (*see* Filing No. 39-1 ¶¶ 28(a), 37(a)). As of today, if the injunction were to be denied, and the parents returned to work, there would be no one to provide the thirty to forty hours of care the Individual Plaintiffs require. Accordingly, IPAS has made the necessary showing that the Individual Plaintiffs will suffer some measure of irreparable harm in the absence of injunctive relief.

# C. <u>Balance of Harms and the Public Interest</u>

The final two questions are whether the balance of harms weigh in favor of preliminary relief and whether the public will benefit from the proposed preliminary injunction. These factors may be viewed together. The Court "weighs the balance of potential harms on a 'sliding scale' against the movant's likelihood of success: the more likely he is to win, the less the balance of harms must weigh in his favor; the less likely he is to win, the more it must weigh in his favor." *Turnell v. CentiMark Corp.*, 796 F.3d 656, 662 (7th Cir. 2015).

IPAS asserts that the balance of harms and public interest both favor preliminary injunctive relief because FSSA cannot claim substantial harm from being forced to continue providing the same care that is has been providing to the Individual Plaintiffs for years. In contrast, FSSA asserts that the balance of harms and public interest weigh against injunctive relief. Specifically, FSSA

argues that "[IPAS] seek[s] an injunction that would violate the federally-approved waiver and place the State at risk of not receiving federal reimbursement." (Filing No. 37 at 35.)

The Court understands FSSA's concern that granting the injunction the Individual Plaintiffs seek *could* place the state at risk of not receiving federal reimbursement. But the Court must also note that FSSA has willingly chosen to violate the federally-approved waiver for years, and even after the filing of this lawsuit, agreed to continue violating the waiver until September 1, 2024, with no threat of the federal government withholding reimbursement. However, should the Court grant the preliminary injunction sought and the state lose its funding, the harm to both FSSA and the public would be grave – no one, including the Individual Plaintiffs, would receive Medicaid services. The court of the federal government withholding reimbursement.

In other words, if the Court granted the injunctive relief sought by the Plaintiffs, the harm to FSSA and the public would outweigh the harm to the Individual Plaintiffs, despite IPAS demonstrating a great likelihood of success. However, there is still recourse for the Individual Plaintiffs (*see infra* III(E)), if the Court grants a modified form of injunctive relief which avoids irreparable harm to FSSA.

## D. Rule 65(c) Bond

Under Federal Rule of Civil Procedure 65(c), a court may issue a preliminary injunction "only if the movant gives security in an amount that the court considers proper to pay the costs and damages sustained by any party found to have been wrongfully enjoined or restrained." Fed. R. Civ. P. 65(c). However, in contrast with this rule, "a number of cases allow a district court to waive

\_

<sup>&</sup>lt;sup>16</sup> Under the A&D Waiver, FSSA allowed LRIs to be reimbursed for providing ATTC despite it being in direct violation of 42 C.F.R. § 440.167. At oral argument, FSSA blamed this violation on automated approvals.

<sup>&</sup>lt;sup>17</sup> Even if the Court construed IPAS' request to allow the Individual Participants to provide ATTC under the newly created H&W Waiver, as presently written, it would still violate 42 C.F.R. § 440.167 resulting in possible loss of Medicaid funding.

the requirement of an injunction bond." *Habitat Educ. Ctr. v. United States Forest Serv.*, 607 F.3d 453, 458 (7th Cir. 2010). A district court may balance the cost to the opponent of a smaller bond against the cost to the applicant of having to do without a preliminary injunction that he may need desperately. *Id.* 

This case involves a challenge brought forth by IPAS on behalf of Medicaid-enrolled children with significant and complex medical needs. Medicaid provides health coverage to low-income individuals and families. It would be counter to the ADA and federal Medicaid law to condition the Individual Plaintiffs' right to receive necessary medical care on their financial status. See Wayne Chem., Inc. v. Columbus Agency Serv. Corp., 567 F.2d 692, 701 (7th Cir. 1977) ("Under appropriate circumstances bond may be excused ... [i]ndigence is such a circumstance") (internal citations omitted). Additionally, FSSA has not argued a likelihood of money damages or requested a bond. Accordingly, Rule 65(c)'s bond requirement is waived.

# E. Scope of the Injunction

Despite the Court's finding that IPAS has demonstrated all the necessary factors to establish a likelihood of success on its ADA and Rehabilitation Act claims, the Court is unable to grant the injunction that Plaintiffs seek. *See Vaughn*, 968 F.3d at 827 (2020) (The Individual Plaintiffs are only "entitled to receive at-home care by providers of [their] choosing to the extent that, working with the State, [they] can craft a relief that complies with federal and state law and does not deprive Indiana of the ability to receive its share of federal reimbursement through the Medicaid program for services provided"). The injunction IPAS requests is as follows:

[E]njoining the defendants to allow the Individual Plaintiffs to continue receiving medically necessary attendant care services through the Aged and Disabled Medicaid Waiver Program, including services provided by their parents, and enjoining the defendants from enforcing against the Individual Plaintiffs the restriction on the provision of attendant care services by legally responsible individuals.

(Filing No. 9 at 1.) This requested injunctive relief presents a novel issue; when a plaintiff is entitled to injunctive relief but the relief they request would violate federal regulations, what is the appropriate remedy?

At oral argument, Plaintiffs argued, and the Court agrees, "there is no doubt in anyone's mind that what these mothers do for their children is extraordinary in every sense of the word." The requested preliminary injunctive relief only violates current Medicaid regulations because of the way FSSA has drafted the H&W Waiver (*i.e.*, deciding not to distinguish extraordinary care from ordinary care). The possibility of a permanent injunction is strong. A permanent injunction would not violate Medicaid law because FSSA could be required to outline criteria for extraordinary versus ordinary care. However, this relief is not feasible at present because it could result in irreparable harm to FSSA should they rewrite the H&W Waiver and later succeed in this case.

When we parse through the arguments presented by IPAS, ultimately they are asking for the Individual Plaintiffs to be provided with the medical assistance they require without being institutionalized. Although this Court is not a professional healthcare administrator, and it does not know what exactly will work, based on the evidence presented by the parties, skilled nursing services and reimbursement of SFC should be sufficient to provide the Individual Plaintiffs with the care they require. *See O.B.*, 838 F.3d at 844 (Easterbrook, J., concurring). In this Order, the Court attempts to provide injunctive relief to sustain the Individual Plaintiffs during this litigation, as they to pursue a permanent injunction.

Accordingly, the Court **grants** IPAS' Motion for Preliminary Injunction but **must modify** the relief it seeks.

## IV. <u>CONCLUSION</u>

For the reasons stated above, Plaintiffs' Motion for Preliminary Injunction is **GRANTED** (Filing No. 9). Pursuant to Federal Rule of Civil Procedure 65(d), the Court **ISSUES A PRELIMINARY INJUNCTION ORDERING** Defendants to take immediate and affirmative steps to (1) arrange directly or through referral to appropriate agencies, organizations, or individuals, corrective treatment of in-home skilled nursing services to E.R. for a minimum of forty hours and G.S. for a minimum of eighty hours per week and, (2) reimburse the mothers for providing SFC in conjunction. Plaintiffs need not post a bond.

#### SO ORDERED.

Date: 8/30/2024

Hon. Tanya Walton Pratt, Chief Judge

United States District Court Southern District of Indiana

#### DISTRIBUTION:

Gavin Minor Rose ACLU OF INDIANA grose@aclu-in.org

Samuel Mark Adams Indiana Disability Rights samadams@indianadisabilityrights.org

Stevie J. Pactor ACLU OF INDIANA spactor@aclu-in.org

Thomas E. Crishon Indiana Disability Rights tcrishon@indianadisabilityrights.org

Harmony A. Mappes FAEGRE DRINKER BIDDLE & REATH LLP (Indianapolis) harmony.mappes@faegredrinker.com

Matthew Richard Elliott
FAEGRE DRINKER BIDDLE & REATH LLP (Indianapolis)
matthew.elliott@faegredrinker.com

Melinda Hudson Faegre Drinker Biddle & Reath LLP melinda.hudson@faegredrinker.com

Ryan Michael Hurley FAEGRE DRINKER BIDDLE & REATH LLP (Indianapolis) ryan.hurley@Faegredrinker.com