IN THE
UNITED STATES DISTRICT COURT
SOUTHERN DISTRICT OF INDIANA
INDIANAPOLIS DIVISION

INDIANA PROTECTION AND ADVOCACY SERVICES COMMISSION, E.R., by his mother and next friend Jessica Carter, and G.S., by his mother and next friend Heather Knight,	)	
Plaintiffs,	)	
v.	)	No. 1:24-cv-00833
INDIANA FAMILY AND SOCIAL SERVICES ADMINISTRATION, the SECRETARY OF THE INDIANA FAMILY AND SOCIAL SERVICES ADMIN., in his official capacity, and the DIRECTOR OF THE DIVISION OF DISABILITY AND REHABILITATIVE SERVICES, in her official capacity,	)	
Defendants.	)	

COMPLAINT FOR DECLARATORY AND INJUNCTIVE RELIEF

Introductory Statement

1. This is a legally complex case about medically complex children. The Indiana Protection and Advocacy Services Commission ("IPAS") is the federally designated protection-and-advocacy system for the State of Indiana, with statutory authority to pursue legal redress on behalf of Hoosiers with disabilities. The individual plaintiffs, as well as numerous other constituents of IPAS, are minors with medically complex disabilities enrolled in Indiana's Aged and Disabled Medicaid Waiver Program ("A&D Waiver"), a home and community-based waiver program approved by the federal government under 42 U.S.C. § 1396n(c), which generally allows for home-based services to be provided as an alternative to institutional care. Despite the fact that their

medical conditions necessitate constant or near-constant care from skilled providers—who are trained, for instance, to administer feedings through a gastronomy tube, to operate a ventilator and other medical devices, to monitor dangerous seizure activity, and to administer daily medications—the Indiana Family and Social Services Administration ("FSSA") has failed in its mandatory duty under federal Medicaid law to ensure that this medically necessary care is available in the community to the individual plaintiffs and other children enrolled in the A&D Waiver. For years, this shortcoming has been papered over by the fact that FSSA allowed the parents and guardians of these children to serve as providers of "attendant care" services through the waiver program. Although not "skilled" providers in the traditional sense of the word, these parents and guardians have typically been trained in their children's unique needs by their children's medical staff, and allowing them to provide (and to be reimbursed for providing) these services enabled them to remain at home to serve as their children's primary caregiver to ensure that their children can remain safe and secure and that their medical needs are met in the community.

2. Beginning July 1, 2024, however, this option will no longer be available. This is because FSSA has made the determination that, effective on that date, parents will no longer be permitted to provide attendant care services to their own children. This is so even though no providers *other* than parents are able to provide these medically necessary services to their children, for even where providers are theoretically available these providers have not been trained, and by service definition are not able, to care for children with complex medical needs. And, while FSSA will allow parents to serve as providers of a similar service, known as "structured family caregiving," not only does FSSA fail to ensure that providers of this service are paid a livable wage (they are not) but, in order to receive this service, families must forego other services necessary for their

children.

3. For a variety of reasons, FSSA's actions run afoul of federal Medicaid law. They also place children at risk of requiring institutionalization and therefore violate the "integration mandate" of the Americans with Disabilities Act of 1990 and the Rehabilitation Act of 1973. Prompt declaratory and injunctive relief is necessary, not only for the individual plaintiffs but also for the hundreds of similarly situated persons, all constituents of IPAS, who will be similarly harmed by FSSA's contemplated changes to the A&D Waiver.

Jurisdiction, Venue, and Cause of Action

4. The Court has jurisdiction of this case pursuant to 28 U.S.C. § 1331.

5. Venue is proper in this district pursuant to 28 U.S.C. § 1391.

6. Declaratory relief is authorized by Rule 57 of the Federal Rules of Civil Procedure and 28 U.S.C. §§ 2201 and 2202.

7. This action is brought pursuant to the Rehabilitation Act of 1973, 29 U.S.C. § 794, *et seq.*, the Americans with Disabilities Act of 1990, 42 U.S.C. § 12101, *et seq.*, and 42 U.S.C. § 1983 to redress the deprivation, under color of state law, of rights secured by federal law.

Parties

8. Indiana Protection and Advocacy Services Commission ("IPAS") is an entity, 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.* It is the state-designated Protection and Advocacy system for the State of Indiana under the Developmental Disabilities Assistance and Bill of Rights Act of 2000, 42 U.S.C. § 15001, *et seq.*, the Protection and Advocacy for Individuals with Mental Illness Act of 1986, 42 U.S.C. § 10801, *et seq.*, and the Protection and Advocacy of Individual Rights Act, 29 U.S.C. § 794e, *et seq.* IPAS's

offices are located in Indianapolis, Indiana. As authorized by statute, IPAS oversees Indiana Disability Rights (https://www.in.gov/idr), its service arm.

9. E.R. is a minor resident of Lawrence County, Indiana. He brings this action by his mother and next friend, Jessica Carter.

10. G.S. is a minor resident of Johnson County, Indiana. He brings this action by his mother and next friend, Heather Knight.

11. The Indiana Family and Social Services Administration is the state agency responsible for, *inter alia*, operating certain social service and financial assistance programs, including the Medicaid program.

12. The Secretary of the Indiana Family and Social Services Administration is the duly appointed head of that agency. He is sued in his official capacity.

13. The Director of the Division of Disability and Rehabilitative Services, a subagency of the Indiana Family and Social Services Administration, is the duly appointed head of that division. She is sued in her official capacity.

Home and Community-Based Medicaid Waiver Programs in Indiana

Background to Medicaid Waiver Programs

14. 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.

15. 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.

16. 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]."

17. As described in 42 U.S.C. § 1396n(c)(3), the requirements of federal Medicaid law subject to "waiver" under a home and community-based waiver program are those established by 42 U.S.C. § 1396a(a)(1) (requiring that the program "be in effect in all political subdivisions of the State"), 42 U.S.C. § 1396a(a)(10)(B) (requiring that medical assistance made available to an individual "not be less in amount, duration, or scope" than the medical assistance made available to other individuals), or 42 U.S.C. § 1396a(a)(10)(C)(i)(III) (relating to income and resource requirements for eligibility).

18. In other words, if approved by the federal government, a participating state may be relieved from its obligation to comply with certain requirements of federal Medicaid law in order to allow it to provide home and community-based services to Medicaid recipients who would otherwise require institutionalization.

19. A waiver granted by the federal government under 42 U.S.C. § 1396n(c) is granted for an initial term of three years but is subject to being extended for additional five-year periods.

20. Pursuant to 42 C.F.R. § 440.180, 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."

21. An individual enrolled in a home and community-based waiver program approved by the

federal government may also receive services through the traditional Medicaid program. In Indiana, these services available through the traditional Medicaid program are often referenced as "prior authorization services"—as, with some exceptions, the receipt of these services is contingent on their advance approval by the Indiana Family and Social Services Administration ("FSSA"), *see* Ind. Admin. Code tit. 405, r. 5-3-1, *et seq.*—or as "state plan services."

22. The full list of services that may be received through the Medicaid program, whether through a home and community-based waiver or otherwise, is enumerated in the definition of "medical assistance" at 42 U.S.C. § 1396d(a). Additional services include early and periodic screening, diagnostic, and treatment ("EPSDT") services for children under the age of 21 (§ 1396d(a)(4)(B)), private duty nursing services (§ 1396d(a)(8)), and "other diagnostic, screening, preventive, and rehabilitative services" (§ 1396d(a)(13)).

23. Under federal Medicaid law, "personal care services" received through the traditional Medicaid program may not be provided by "a member of the individual's family," 42 U.S.C. § 1396d(a)(24), a term that is defined to include only "legally responsible relatives"—that is, spouses of adult recipients and parents or stepparents of minor recipients. *See* 42 C.F.R. § 440.167(b); 62 Fed. Reg. 47896, 47899 (1997). States have discretion, however, to define "personal care services" differently for purposes of a waiver program. *See* 42 C.F.R. § 440.167. This discretion extends to allowing "legally responsible relatives" to provide these services.

24. There is no federal restriction on "legally responsible relatives" providing any service other than "personal care services" to Medicaid enrollees, whether through traditional Medicaid or through a waiver program.

25. Indiana participates in the Medicaid program and is subject to all of the requirements of federal Medicaid law. In Indiana, the Medicaid program is administered by FSSA.

The Aged and Disabled Medicaid Waiver Program in Indiana

26. Consistent with 42 U.S.C. § 1396n(c), Indiana operates—through FSSA—multiple home and community-based Medicaid waiver programs, including the Aged and Disabled Medicaid Waiver Program ("A&D Waiver"). Although previously operated by the Division of Aging within FSSA, the A&D Waiver is currently operated by the Division of Disability and Rehabilitative Services.

27. Through the A&D Waiver, FSSA provides home and community-based services to persons who it has determined meet "nursing facility level of care"—that is, for persons who, in the absence of these services, would require placement in a nursing facility.

28. The most recent federally approved renewal of the A&D Waiver took effect on July 1, 2023 and, unless amended, will remain in effect through June 30, 2028. The formal application for this renewal, which has been approved by the federal government, is available at https://www.in.gov/fssa/da/files/A-and-D_waiver_Jan2023.PDF (last visited Apr. 11, 2024) and is incorporated herein by reference. As specified in this waiver application, FSSA anticipates that the A&D Waiver will serve 47,680 persons each year from 2023 through 2027.

29. 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. § 1396a(a)(10)(B) (related to comparability).

30. Through the A&D Waiver, participants may receive specific types of services, detailed in the federally approved waiver application, that are intended to ensure that their needs are met and that they are able to reside safely and securely in the community. The types of services, service definitions, and any limitations imposed on the provision of each service category are determined by FSSA and are not mandated by the federal government aside from the federal government's

role in approving the waiver program.

31. Each individual enrolled in the A&D Waiver is assigned a case manager employed by a contractor of FSSA. At least once a year, and more often if necessary, that case manager—with the input of the waiver recipient and, where appropriate, their family—is responsible for submitting a proposed service plan to FSSA for approval. The service plan details the types and amount of services that the waiver recipient may receive each year. This service plan must be approved by FSSA before it takes effect.

32. While a recipient may not receive *more* services through the A&D Waiver than detailed in their service plan, for a variety of reasons they might receive *fewer* services than detailed in that plan. This might be the case, for instance, if they have difficulty finding available providers to perform the services detailed in the plan or if they have a hospital stay or other event that causes them not to utilize services for a period of time.

33. As is relevant to this case, enrollees in the A&D Waiver may receive "attendant care services" or "structured family caregiving." On information and belief, both attendant care services and structured family caregiving are intended by FSSA to constitute "personal care services" under 42 U.S.C. § 1396d(a)(24).

34. Attendant care services, which are often abbreviated "ATTC," are services 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. 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. However, attendant care services are 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.

35. Presently, there is no "cap" on the amount of attendant care services that an individual enrolled in the A&D Waiver may receive beyond the requirement that their case manager must determine all services to be medically necessary for the individual.

36. Structured family caregiving services, which are often abbreviated "SFC," are defined by the formal A&D Waiver document as "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." 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. However, like attendant care services, structured family caregiving services are 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."

37. Pursuant to the terms of the A&D Waiver, personal care or similar services—including both attendant care services and structured family caregiving—may not be provided by "Legally Responsible Individuals," or LRIs, a term that means the same thing as the term "legally responsible relative" in 42 C.F.R. § 440.167(b). An LRI 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.

38. Despite the terms of the formal A&D Waiver, in order to meet the needs of individuals enrolled in that program, FSSA has long allowed parents, guardians, or other LRIs to provide the attendant care services that are received by their loved ones, and has reimbursed providers for these services.

39. For some waiver recipients and their families, this is a matter of choice. But for a great number of them, it has been an absolute necessity. This is so for a variety of reasons.

40. For one, many persons enrolled in the A&D Waiver have complex medical needs that necessitate the presence at all times of a caregiver who is trained to provide the specific forms of care and supervision that they require. This might include feeding a recipient through a G-tube, monitoring a recipient's seizure activity, administering a recipient's medications, or in some cases even operating a ventilator or other medical equipment. Even though LRIs are not nurses or other skilled professionals, often they have been taught by their loved ones' medical providers to respond to these unique needs and to provide the specific care that their loved ones require. An attendant care provider who is not an LRI with this training will be incapable of providing and unqualified to provide the care and supervision that a waiver recipient with complex medical needs requires and, indeed, even were attendant care providers permitted by FSSA to perform these specialized tasks (which they are not), it is virtually impossible that any home health agency would assign a non-LRI attendant to care for such an individual.

41. Additionally, some persons—particularly those who live in rural communities—are unable to find or otherwise recruit an attendant care provider who is willing and able to serve their family member enrolled in the A&D Waiver. In order to ensure the health and safety of these persons, and their ability to continue residing in the community, LRIs have obtained employment with agencies providing attendant care services specifically so that they may serve their loved ones. To do so, they have often been required to give up other employment.

42. And some persons enrolled in the A&D Waiver, due to their medical conditions, have severely compromised immune systems such that their introduction to any foreign bodies could jeopardize their health or even threaten their life. For these persons, it is fundamentally important

that they be allowed to receive attendant care services from their LRIs simply as a means of limiting the number of persons with whom they interact. After all, regularly interacting with a different attendant would exponentially increase the risks associated with their compromised immune system, particularly if the attendant provides care to other persons with illnesses or has children of their own.

43. An individual who receives structured family caregiving through the A&D Waiver may not also receive attendant care services—from anyone, even non-LRIs—through that program.

44. FSSA establishes rates at which it will reimburse each service provided through the A&D Waiver. Beginning July 1, 2024, FSSA anticipates that it will reimburse attendant care services at a rate of $34.36 an hour. It anticipates that it will reimburse structured family caregiving providers at a rate of between $77.54 and $133.44 a day, depending on the assessed level of need.

45. However, because individuals who provide attendant care services or structured family caregiving are typically employed by private companies enrolled as providers in the Medicaid program, these rates include costs pertaining to program support as well as administrative costs. FSSA estimates that at most 60% of the hourly rate for attendant care services (or $20.62) will be provided to the individual caregiver, and that between 65% and 70% of the daily rate for structured family caregiving (or between $50.40 and $93.41) will be provided to the individual caregiver. The precise compensation to be provided 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.

46. Despite its longstanding awareness that LRIs have been allowed to provide, and have been reimbursed for providing, attendant care services through the A&D Waiver, FSSA has not sought to amend the formal document governing the A&D Waiver to specifically allow LRIs to provide

these services. At all times, however, it has had the authority to do so.

Home Health Aide Services Available to Enrollees in the A&D Waiver

47. As noted, persons enrolled in a home and community-based Medicaid waiver program, including the A&D Waiver, may also be eligible to receive "prior authorization services" through the traditional Medicaid program. These services include home health aide services provided by a home health agency.

48. Pursuant to regulations promulgated by FSSA, home health aide services may not be provided to a Medicaid recipient unless they are, *inter alia*, medically necessary and "[l]ess expensive than any alternate modes of care." Ind. Admin. Code tit. 405, r. 5-16-3.1(a)(5)-(6). Even then, except for ventilator-dependent patients, they may only be provided on an "[i]ntermittent or part time" basis. Ind. Admin. Code tit. 405, r. 5-16-3.1(a)(3).

49. The plaintiffs are unaware as to whether home health aide services are "[l]ess expensive" on an hourly basis than attendant care services. However, for patients that require constant or near-constant care and supervision, they are certainly not "[l]ess expensive" than structured family caregiving services, which are reimbursed at a per diem rate.

50. Regardless, for many of the same reasons that patients with complex medical needs are unable to receive attendant care services from persons other than their family members, non-family members are not able to provide home health aide services to these persons. Aside from difficulties finding or otherwise recruiting a home health aide to serve some A&D Waiver recipients, like an attendant care provider, a home health aide who is not an LRI will be incapable of providing and unqualified to provide the care and supervision that a waiver recipient with complex medical needs requires. Indeed, even were home health aides permitted by FSSA to perform these specialized tasks (which they are not), it is virtually impossible that any home health agency would assign a

non-LRI aide to care for such an individual.

51. On top of this, the overwhelming majority of LRIs and other family members of enrollees in the A&D Waiver are similarly unable to provide home health aide services to their loved ones. This is because, unlike attendant care services, 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. 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). And Indiana law imposes additional continuing education requirements. *See* Ind. Admin. Code tit. 410, r. 17-14-1(h).

52. In other words, home health aide services may only be provided by a certified home health aide, and most family members of A&D Waiver enrollees are simply not certified home health aides. And, even were it permissible for FSSA to require that they attempt to *become* certified home health aides, they are not able to do so without the expenditure of significant time and resources that most family members of medically complex children simply do not have.

Changes to the A&D Waiver to Take Effect on July 1, 2024

53. In 2023, FSSA discovered that its agency-wide budget forecast had missed the mark by approximately $986 million. This discovery caused an internal review of multiple programs operated by FSSA, including the A&D Waiver and, due in part to this review, FSSA announced that it will dramatically curtail the ability of LRIs to provide services to waiver recipients.

54. Beginning January 17, 2024, FSSA began prohibiting new LRIs—that is, those who were not already providing attendant care services to A&D Waiver recipients—from beginning to provide attendant care services to enrollees in that program.

55. FSSA has further announced that, beginning July 1, 2024, *all* A&D Waiver enrollees will

for the first time be prohibited from receiving attendant care services from LRIs.

56. As noted, the formal A&D Waiver document currently prohibits LRIs from serving as providers of structured family caregiving services as well as attendant care services. In apparent recognition of the fact that some waiver enrollees cannot be served by anyone other than their LRIs, it is the plaintiffs' understanding that FSSA has submitted a proposal to the federal government requesting that the A&D Waiver be formally amended. Under this proposal, if approved, current enrollees in the A&D Waiver who are under sixty years old—a total of about 11,000 persons—will be transitioned to a new home and community-based waiver program known as the Health and Wellness Waiver Program ("H&W Waiver"). These individuals would then be allowed to receive structured family caregiving services, but not attendant care services, from LRIs.

57. Under the H&W Waiver, recipients would be allowed to elect to receive attendant care services from non-LRI providers but, if they did so, would not also be able to receive structured family caregiving services. Conversely, recipients who received structured family caregiving from LRIs would not be able to also receive attendant care services—from anyone. In other words, the two services are mutually exclusive.

58. The inability of LRIs to provide attendant care services through the A&D Waiver (or, if approved, the H&W Waiver) will have a devastating impact on numerous waiver enrollees and their families.

59. If LRIs are not permitted to provide structured family caregiving—that is, if FSSA's proposed changes to the waiver program are not approved—the impact is self-evident. As noted, for a variety of reasons, many waiver enrollees, particularly those with complex medical needs, do not have the ability to receive necessary personal care services from persons other than their LRIs.

This means that they will have no ability to receive medically necessary services at all and, instead, many of their LRIs will be forced to seek employment outside of the home as they will no longer be able to receive compensation for providing care to their loved ones. For large parts of every day, this will of course prevent them from providing the necessary care and supervision that their loved ones require. The health and safety of waiver enrollees will thus be placed in grave danger and they will be denied medically necessary care to which they are entitled under the Medicaid program.

60. Even if FSSA's proposed changes to its waiver program are approved, such that LRIs are permitted to provide structured family caregiving but not attendant care services to waiver enrollees, this harm will scarcely be alleviated. After all, for two primary reasons the ability to receive structured family caregiving services from LRIs will not alleviate the impact of the inability to receive attendant care services from LRIs:

a. First, as noted, the reimbursement rate provided by FSSA to providers of structured family caregiving services pales in comparison to the reimbursement rate provided to providers of attendant care services. For many LRIs, the ability to receive between $50.00 and $90.00 a day—a rate of, at most, approximately $12.00 an hour, assuming an eight-hour day (although in reality they work far more than eight hours each day)—will not obviate the need for them to obtain employment outside of the home. But were they to obtain such employment, their loved ones enrolled in the waiver program would not have anyone to provide necessary care and supervision during this period of time.

b. And second, as noted, any waiver recipient who receives structured family caregiving services may not also receive attendant care services—from anyone, at any time. Because some recipients require constant care and supervision, their primary caregivers (who are

typically LRIs) currently may rely on other persons (who may be non-LRI members of their family or family friends) to provide attendant care services for a limited period of time so that they may sleep or tend to other necessary responsibilities. Indeed, some recipients with significant needs require the presence of a second caregiver at times to assist them with transfers, with bathing, or with other medically necessary activities that cannot be accomplished by a single caregiver. None of this, however, would be possible if the waiver recipient receives structured family caregiving services.

61. Nor is the harm to patients alleviated by the existence of home health aide services through the traditional Medicaid program. As noted, these services may only be provided on an "[i]ntermittent or part time" basis. That limitation aside, they cannot be provided by the LRIs of most enrollees in the A&D Waiver insofar as, unlike either attendant care services or structured family caregiving, they may only be provided by persons who have received a formal certification after meeting substantial education, training, and evaluation requirements. And they cannot be provided to children with complex medical needs by non-LRI home health aides because, like non-LRI attendant care providers, these persons are not trained and qualified to provide the skilled assistance that medically complex children require.

62. Some persons denied medically necessary care as a result of FSSA's changes to the A&D Waiver will be at great risk of requiring placement in an institutional environment or will actually require this placement. On information and belief, there are only two nursing homes in Indiana that serve pediatric patients and so, for many medically complex children, the only institutional environment available to them may be as a permanent inpatient in a hospital.

FSSA's Failure to Provide Necessary Services to Enrollees in the A&D Waiver

63. Under federal Medicaid law, FSSA has the duty to provide, or ensure the provision of,

medically necessary services to enrollees in the A&D Waiver, including services necessary to ensure that enrollee's skilled needs—such as administering a ventilator or gastronomy tube (G-tube), closely monitoring and responding to seizure activity, or administering medications—are met. These services might be provided as "medical care" (42 U.S.C. § 1396d(a)(6)), "private duty nursing services" (42 U.S.C. § 1396d(a)(8)), or even "preventive . . . services" (42 U.S.C. § 1396d(a)(13)).

64. Most if not all medically complex children enrolled in the A&D Waiver are eligible to receive services through the Medicaid program capable of ensuring that their medical needs are met. Regardless of whether or not the provider is an LRI, these services may not be provided as attendant care services or structured family caregiving for, as noted, FSSA has defined these services to exclude activities traditionally performed by a "skilled" provider.

65. If and when a provider submits a request for FSSA to approve these services on behalf of a medically complex child, FSSA will approve Medicaid reimbursement for these services to the extent that it determines these services to be medically necessary.

66. On information and belief, however, FSSA takes no other meaningful steps to ensure that medically complex children enrolled in the A&D Waiver have access to services necessary to meet their medical needs, whether these services are provided through the A&D Waiver or through the traditional Medicaid program. As a matter of fact, then, FSSA has failed and continues to fail in its duty to ensure that these children, including the individual plaintiffs and the other constituents of IPAS, receive services that are medically necessary to ensure that their complex medical needs are met.

67. For years, this shortcoming has been papered over by FSSA's willingness to allow the LRIs of these children to provide attendant care services through the A&D Waiver. In the absence of

FSSA ensuring the availability of providers to care for these children, this decision allowed for LRIs trained in their children's needs to care for their medically complex children while receiving a livable wage as providers of attendant care services, even if these services did not allow for the reimbursement of "skilled" care.

68. Beginning July 1, 2024, however, this will no longer be possible. For the reasons noted above, neither allowing LRIs to serve as providers of structured family caregiving services nor the existence of home health aide services through the traditional Medicaid program is an adequate substitute either to allowing LRIs to serve as providers of attendant care services or to ensuring that medically complex children receive the services necessary to meet their medical needs.

69. FSSA therefore will be forcing the families of medically complex children enrolled in the A&D Waiver into an impossible situation: because it has failed in its duty under federal Medicaid law to ensure the availability of services necessary to meet children's medical needs, the only option available to LRIs—short of exploring the unfathomable possibility of having their children institutionalized or allowing their children's needs to go unmet—is to serve as providers of structured family caregiving services to their children.

70. But this is not a viable solution either. Not only does structured family caregiving continue to fail to provide medically complex children with the "skilled" care that they require but, as noted, FSSA's reimbursement rate for providers of structured family caregiving services pales in comparison to its reimbursement rate for providers of attendant care services. Many LRIs of children enrolled in the A&D Waiver will thus not receive a livable wage if they are forced to serve as structured family caregivers. Some of these persons may be forced to consider having their children institutionalized; others will be forced to make decisions that, at the very least, threaten their children's safety and quality of life.

71. On top of this, once again, any child who receives structured family caregiving services through the A&D Waiver will not be able to also receive attendant care services—from anyone. This is so even though some LRIs have relied on the ability of attendant care providers familiar with their children's medical needs—often a non-LRI family member or a close friend—to provide care during times when the LRIs are not able to do so. The restriction on receiving any attendant care services if a child enrolled in the A&D Waiver is also receiving structured family caregiving services thus constitutes a denial of medically necessary care.

The Indiana Protection and Advocacy Services Commission and its Constituents

72. As noted, IPAS is the designated Protection and Advocacy system for the State of Indiana under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 ("DD Act"), 42 U.S.C. § 15001, *et seq.*, the Protection and Advocacy for Individuals with Mental Illness Act of 1986 ("PAIMI Act"), 42 U.S.C. § 10801, *et seq.*, and the Protection and Advocacy of Individual Rights Act ("PAIR Act"), 29 U.S.C. § 794e, *et seq.*

73. The federal statutes pursuant to which IPAS has been established generally give IPAS the authority to pursue legal remedies to ensure the protection of persons with disabilities who are receiving care or treatment in Indiana. *See* 29 U.S.C. § 794e(f)(3) (PAIR Act); 42 U.S.C. § 10805(a)(1)(B) (PAIMI Act); 42 U.S.C. § 15043(a)(2)(A)(i) (DD Act).

74. Protecting the rights of persons enrolled in the A&D Waiver to receive vital services through the Medicaid program is both germane to IPAS's purpose and consistent with the authority that has been vested in it by Congress.

75. IPAS therefore brings this action on behalf of persons enrolled in the A&D Waiver who will be detrimentally affected by FSSA's anticipated changes to the A&D Waiver and by its failure to ensure that persons are provided adequate and necessary care through the Medicaid program.

These persons are IPAS's constituents.

The Individual Plaintiffs and Their Legally Responsible Individuals

76. Some of the problems with FSSA's anticipated changes to the A&D Waiver, to take effect for existing waiver enrollees on July 1st, are evidenced by the individual plaintiffs and their families.

E.R. and His Family

77. E.R. is a minor resident of Mitchell, Indiana. Mitchell is a small, rural city in Lawrence County, about 45 minutes south of Bloomington and 75 minutes northwest of Louisville, Kentucky.

78. E.R. is six years old and resides with his mother, Jessica Carter, as well as his 19-year-old sister.

79. E.R. has cri-du-chat syndrome, a rare genetic disorder caused by a missing section of a particular chromosome. He spent the first fifteen days of his life in the neonatal intensive care unit (NICU) and, when his condition deteriorated in his infancy, he was required to live in the hospital for approximately 18 months between 2019 and 2021. At present, he takes 17 different medications daily.

80. As a result of his cri-du-chat syndrome, E.R. has a wide variety of medical diagnoses and symptoms. He has chronic lung disease, severe respiratory issues, and epilepsy that results in significant seizures that are not fully controlled by medication. 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. Even though he is six years old, developmentally he resembles a 9-month-old. He requires close, 24/7, care and supervision and assistance with all of his activities of daily living.

81. Given his disabilities, E.R. is a constituent of IPAS.

82. While the complexity of E.R.'s medical needs impacts every aspect of his life and his family members' lives, three aspects of his daily care require particularly close attention and the presence of a skilled caregiver at all times:

a. First, E.R. routinely experiences severe seizures that require close attention. While his seizure activity has been partially controlled through medication, every month or two he will experience a serious seizure that lasts thirty or forty minutes. These seizures can be extremely violent and have resulted in E.R. stopping breathing entirely during the course of the seizure. E.R.'s mother has been informed by his medical providers that the failure to respond promptly and appropriately to a severe seizure could lead to substantial, irreparable damage to E.R. and could threaten his life. Because of this, E.R. must have someone awake with him at all times.

b. Second, E.R. is unable to consume food himself and so is fed exclusively through a G-tube, and is fed in that manner several times each day. During waking hours, he is typically fed every three hours for a half-hour each feed. In addition to administering E.R.'s actual feedings, his mother is also responsible for cleaning daily the G-tube site and for monitoring the site for signs of infection or blockage.

c. And third, E.R. has severe respiratory distress. Until only the past few months, E.R. had a tracheostomy and was placed on a ventilator at home. While he has recently been removed from the ventilator, he still relies on a CPAP machine for assistance breathing much of the time. The tracheostomy and ventilator, however, caused serious, long-term damage to E.R.'s airway and he will require surgery in a couple of years to reconstruct his airway: his medical team has determined that they must wait for his airway to further develop before surgery can safely be performed. Until that time, E.R. and his family visit Cincinnati Children's Hospital twice a week in order to ensure that he is properly prepared for this surgery, and Ms. Carter is responsible for closely monitoring his respiratory condition to ensure that she is able to respond promptly to any emergent issues.

83. After being released from the NICU, E.R. resided at home with his mother and sister for approximately the first two years of his life. At that point, however, his condition deteriorated and he was hospitalized at Riley Hospital for Children in Indianapolis for approximately 18 months. During this period of time, he was intubated for 13 months and his family was extremely concerned that they were going to lose him.

84. After E.R. was stabilized in the hospital, his family and his medical providers searched for a lengthy period of time for a skilled professional—that is, a registered nurse—who would be able

to provide in-home care to E.R. so that he could be released back to the community and reside again with his family. They were unable to find anyone willing to provide and capable of providing this care, however, and so instead E.R.'s medical provider spent two months teaching E.R.'s mother, Jessica Carter, and his sister (who was at that time still a minor herself) to provide the care and supervision that E.R. requires on a daily basis.

85. When E.R. was finally released from the hospital in 2021, his medical providers informed his family that he was likely being released on end-of-life measures but that they wanted to allow him to live more comfortably at home during this period. As indicated, however, E.R. has continued to gradually improve and only recently was he finally removed from the ventilator.

86. As a result of E.R.'s various medical conditions and functional limitations, not only does he require constant, 24/7, care and supervision, but he requires the person providing this care and supervision to be capable of providing skilled, nursing care. That is necessary to ensure that he is fed properly through the G-tube, to ensure that he is closely monitored for seizure activity, to ensure that he receives the proper medications in a timely fashion, and to closely monitor his respiratory condition.

87. Beginning in December of 2017, E.R. was approved for and was placed on the A&D Waiver.

88. About six months after being released from the hospital in 2021, E.R.'s family was able to find a registered nurse, paid for through the A&D Waiver, who was able to provide in-home care to E.R. for between twenty and thirty hours a week. This only lasted about six months, however, before that nurse moved out of state to accept a higher paying position and was therefore no longer able to provide care to E.R.

89. Since that time, Ms. Carter has placed E.R.'s name on the wait list at numerous different

nursing agencies in the hope that she will be able to find another skilled professional who is able to provide in-home services to E.R. She checks with these agencies regularly but thus far has had no success. Most if not all of these agencies primarily service adults, and Ms. Carter has been informed that none of them have staff able to provide services in rural Lawrence County. In other words, the lists on which E.R.'s name has been placed are "wait lists" in name only, for there is no end in sight to the search for a skilled professional willing and able to provide services to E.R.

90. 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. If appropriate staff becomes available, this will enable that individual to begin providing services to E.R. immediately without any administrative delay. FSSA has routinely granted this request, and E.R. is currently approved (and has been approved for some time) to receive forty hours each week in skilled nursing services, even though he does not actually receive these services.

91. In 2022, not long after E.R.'s nurse moved out of state and stopped providing care to him, Ms. Carter learned for the first time that E.R. might be eligible to receive attendant care services through the A&D Waiver. When she first discussed this possibility with E.R.'s case manager, his case manager was not even aware of the existence of these services. In follow-up conversations, however, the case manager suggested that, in the absence of a registered nurse who could provide care to E.R., Ms. Carter could obtain employment to serve as E.R.'s provider of attendant care services.

92. In 2022, therefore, Ms. Carter became employed by a Medicaid home care provider specifically to serve as E.R.'s provider of attendant care services, and she has served as E.R.'s primary paid provider of attendant care services through the A&D Waiver since that time. His

only other provider is his 19-year-old sister, who provides attendant care services to E.R. during the nighttime hours to allow Ms. Carter to sleep.

93. Ms. Carter qualifies as an LRI with respect to E.R.

94. While she loves her brother and is able and willing to provide care to E.R. during times that their mother is asleep, E.R.'s sister is not able to provide additional services to E.R. As indicated, she is only nineteen and would like to begin attending college or otherwise start her adult life.

95. Until very recently, Ms. Carter was approved to be reimbursed approximately 112 hours each week to provide care to E.R., and E.R.'s sister was approved to be reimbursed approximately 56 hours each week. This amount of care is medically necessary for E.R. and, other than his family, Ms. Carter is not aware of any skilled or trained providers available to ensure that E.R. receives the care and supervision that he requires without risking his health.

96. Before E.R. was born, Ms. Carter worked outside of the home although she ceased doing so in order to care for E.R. Prior to E.R.'s release from his lengthy hospitalization in 2021, Ms. Carter was able to perform some work as a hair stylist out of her home, and she was able to do this to an even more limited extent while the nurse provided care to E.R. for several days each week. Since the nurse moved out of state, however, Ms. Carter has not been able to work as a hair stylist, even out of her home, given the extent of E.R.'s needs.

97. The income that Ms. Carter has received from providing attendant care services to E.R. has represented her only income for several years.

98. For at least two reasons, transitioning from providing attendant care services to E.R. to providing structured family caregiving to E.R. is not a feasible option for Ms. Carter and her family:

a. First, given the dramatic disparity between the rate at which Ms. Carter would be paid as a provider of structured family caregiving and the rate at which she is paid as a provider of attendant care services, the option is not financially feasible. E.R. and his family do not live an exorbitant lifestyle but Ms. Carter's income as a provider of attendant care services is sufficient to ensure that their basic needs are met. Simply put, the amount of pay that Ms. Carter could expect to receive as a provider of structured family caregiving would not be, and she would be forced to look for additional work. But this is not possible, as E.R. requires constant care and supervision.

b. And second, if E.R. began to receive structured family caregiving services, he could no longer receive attendant care services overnight from his sister. His sister would then be required to find employment outside of the home and would no longer be able to provide this care and supervision to E.R. This would leave Ms. Carter in the impossible situation of having to care for E.R. at all times, and would not allow her to even sleep (or, if she attempted to do so, would place E.R.'s health and safety in severe jeopardy).

99. In April or early May of 2024—even in advance of the July 1st date on which FSSA's proposed changes to the A&D Waiver are to take effect—E.R.'s case manager submitted a request for FSSA to approve a new service plan identifying the services that E.R. will continue to receive through the A&D Waiver. It is Ms. Carter's understanding that the request submitted by E.R.'s case manager would have continued E.R.'s attendant care services at their previous levels.

100. On May 9, 2024, however, FSSA denied the service plan submitted by E.R.'s case manager. It is Ms. Carter's understanding that the plan was denied, in substantial part, because it did not provide that E.R. would receive home health aide services through the traditional Medicaid program.

101. For all the reasons noted above, however, E.R. is not able to receive home health aide services through the traditional Medicaid program. A home health aide not related to E.R. will not be able to provide the care and supervision that his medical conditions require, and Ms. Carter is simply not a certified home health aide. Nor is it realistically possible for Ms. Carter to become a certified home health aide: she spends virtually every waking hour caring for E.R. and has absolutely no idea when she would be able to complete the training and evaluation requirements

to become a home health aide.

102. If FSSA's prohibition on Ms. Carter providing attendant care services to E.R. goes into effect on July 1st, Ms. Carter will likely be forced to return to full-time work outside of the home in order to afford basic necessities for herself and E.R. Because she obviously cannot leave E.R. alone in order to do so, and because there are no other providers willing and able to provide care and supervision to E.R., she may have no option other than to explore having E.R. institutionalized. Because of the limited space available in pediatric nursing homes in Indiana, and because of the complexity of E.R.'s medical needs, it is Ms. Carter's understanding that this might entail bringing E.R. back to the hospital to reside as an inpatient. His primary care team is at Cincinnati Children's Hospital, and so if E.R. returned to hospitalization in all likelihood it would be at that facility although Ms. Carter does not know how that process would work or if FSSA would pay for this out-of-state placement.

G.S. and His Family

103. G.S. is a minor resident of Greenwood, Indiana, a city not far from Indianapolis in Johnson County.

104. G.S. is ten years old and resides with his mother, Heather Knight, as well as three minor siblings.

105. Among other conditions, G.S. has hypoxic-ischemic encephalopathy. This is a type of brain damage, generally caused by a lack of oxygen to the brain before or shortly after birth, that affects the central nervous system and that may cause neurological or developmental problems. He was also born with an 11-millimeter atrial septal defect (or ASD)—quite literally, a hole in his heart—that caused blood to be leaked into his lung.

106. He also experiences progressive white matter brain loss. Although his medical providers

have not determined a cause, this condition results in developmental and intellectual deficits and, as Ms. Knight understands it, also affects his mobility. On top of all this, G.S. has also been diagnosed with Lennox-Gastaut syndrome, a severe condition characterized by repeated seizures.

107. At present, G.S. takes about ten different medications daily.

108. G.S. was born outside of Indiana. Immediately after his birth, he was placed on life support for eight days, during which his medical providers induced hypothermia in order to keep him alive. He spent approximately the first 24 days of his life in the neonatal intensive care unit (or NICU) and then, although he was briefly allowed to go home with his family, after only four days he returned to the hospital's pediatric intensive care unit (or PICU). In the PICU, he was intubated for a month.

109. All told, for approximately the first two years of his life, G.S. cycled between short stays at home with his family and lengthier hospitalizations at hospitals outside of Indiana.

110. In 2016, Ms. Knight moved her family from Kentucky to central Indiana in order to be close to the medical providers at Riley Hospital for Children ("Riley") in downtown Indianapolis. At Riley, G.S. had open heart surgery to repair the atrial septal defect in his heart through the creation and installation of a "patch" to prevent blood from leaking into his lung.

111. Although the surgery was successful, as a result of his atrial septal defect and the leaking of blood into his lung, G.S. has chronic lung disease. When he is at home, G.S. is kept constantly on an oximeter, a medical device that displays his heart rate, blood oxygen saturation level, and other vital signs. This allows Ms. Knight to closely monitor his condition so that she can respond in a timely fashion in the event that she needs to administer supplemental oxygen to G.S.

112. As a result of his various conditions, G.S. is nonverbal and is quadriplegic. He is also deaf. He requires close, 24/7, care and supervision and assistance with all of his activities of daily living.

He has been placed by his medical providers on palliative care, an approach aimed at optimizing quality of life and mitigating suffering among persons with serious, complex, and oftentimes terminal illnesses.

113. Given his disabilities, G.S. is a constituent of IPAS.

114. While the complexity of G.S.'s medical needs impacts every aspect of his life and his family members' lives, three aspects of his daily care require particularly close attention and the presence of a skilled caregiver at all times:

a. First, G.S. routinely experiences seizures that require close attention. Even though he takes seizure medication, his seizures are poorly controlled and he experiences multiple seizures, of varying levels of severity, each day. Because he cannot verbalize his experiences, Ms. Knight is required to closely monitor his seizure activity in order to identify the occurrence, the type, and the severity of each seizure and to respond accordingly. G.S.'s medical providers have developed a plan for when G.S. experiences seizure activity, which may require, among other things, that his mother administer rescue medications or seek emergency medical assistance. The failure to respond promptly and appropriately to a severe seizure could lead to substantial, irreparable damage to G.S. and could threaten his life.

b. Second, G.S. is unable to consume food himself and so is fed exclusively through a G-tube, and is fed in that manner several times each day. In addition to administering G.S.'s actual feedings, his mother is also responsible for cleaning daily the G-tube site and for monitoring the site for signs of infection or blockage. Approximately every two hours—including through the night—either G.S. must be fed through the G-tube or the G-tube must be flushed with water to ensure its cleanliness and to prevent blockage.

c. And third, as noted, G.S. has severe cardiac and respiratory issues that require constant monitoring. Given the severity of his conditions, Ms. Knight must be extremely vigilant to ensure that she notices any change in his behavior or his vital signs and that she responds accordingly.

115. As a result of G.S.'s various medical conditions and functional limitations, not only does he require constant, 24/7, care and supervision, but he requires the person providing this care and supervision to be capable of providing skilled, nursing care.

116. Given his medical travails, G.S.'s immune system is also severely compromised, and he is at great risk of becoming extremely sick if he is introduced to any foreign germs. Even the slightest

illness has the potential to spiral rapidly until it becomes life-threatening. Because he is severely immuno-compromised, Ms. Knight is extremely careful about limiting the number of persons she allows into their home and the foreign bodies to which G.S. is exposed.

117. Beginning in 2017, G.S. was approved for and was placed on the A&D Waiver.

118. After becoming enrolled in the A&D Waiver, G.S. was approved to receive eighty hours each week of in-home skilled nursing services through that program. Prior to the COVID-19 pandemic, he had a nurse that provided this care for approximately forty hours each week. In early 2020, however, his nurse left to accept a job in Chicago.

119. After G.S. lost his nurse, Ms. Knight was unable to single-handedly provide him with the care and assistance that he requires, and she therefore made the difficult decision to place him at Especially Kidz Health and Rehabilitation—one of two pediatric nursing homes in Indiana—in Shelbyville. G.S. resided at this institution from July 3rd through December 23rd of 2020.

120. Unfortunately, this placement proved to be a horrendous experience. G.S.'s quality of life suffered significantly, and Ms. Knight became extremely concerned that staff at the facility were unprepared to ensure that G.S. received the medical care that he requires. Ms. Knight is also concerned that G.S. may have suffered abuse or neglect at the facility. In late 2020, she therefore removed him from the nursing home.

121. In or around late 2021, Ms. Knight learned for the first time that she might be able to serve as G.S.'s paid provider of attendant care services through the A&D Waiver. Late that year, she therefore became employed by a Medicaid home care provider specifically to serve as G.S.'s provider of attendant care services, and she has served as G.S.'s only paid provider of attendant care services through the A&D Waiver since that time.

122. Ms. Knight qualifies as an LRI with respect to G.S.

123. Prior to becoming G.S.'s paid provider of attendant care services through the A&D Waiver, Ms. Knight and her family resided with an adult roommate. At the time, Ms. Knight had been informed that G.S. was likely to pass away in the foreseeable future, and, while she would have preferred to live independently, she made the difficult decision to live with this roommate for two reasons. First, given her need to provide constant care and supervision to G.S., Ms. Knight obviously could not work outside of the home and she could therefore not afford to live independently. And second, she felt that she herself needed emotional support in the event that G.S. did not survive.

124. Due to her employment as a paid provider of attendant care services to G.S., Ms. Knight has been able to move herself and her family into their own home. Returning to live with her previous roommate is not an option.

125. At present, Ms. Knight is reimbursed approximately 86 hours each week to provide care to G.S. (although she provides care and supervision to G.S. for many more hours than this). This amount of care is medically necessary for G.S. and, other than herself, Ms. 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.

126. In addition, G.S. receives approximately nine hours each week—provided in three-hour increments—in respite nursing services through the A&D Waiver. This allows some reprieve for Ms. Knight so that she can go grocery shopping or run other necessary errands but obviously is not close to sufficient to allow Ms. Knight to explore obtaining employment outside of the home.

127. The income that Ms. Knight receives from providing attendant care services to G.S. has represented her only income for several years.

128. Transitioning from providing attendant care services to G.S. to providing structured family

caregiving to G.S. is not a feasible option for Ms. Knight and her family. Given the dramatic disparity between the rate at which Ms. Knight would be paid as a provider of structured family caregiving and the rate at which she is paid as a provider of attendant care services, the option is not financially feasible. G.S. and his family do not live an exorbitant lifestyle but Ms. Knight's income as a provider of attendant care services is sufficient to ensure that their basic needs are met. Simply put, the amount of pay that Ms. Knight could expect to receive as a provider of structured family caregiving would not be sufficient to meet the family's basic needs, and she would be forced to look for additional work. But this is not possible, as G.S. requires constant care and supervision.

129. Nor is G.S. able to receive home health aide services through the traditional Medicaid program. A home health aide not related to G.S. will not be able to provide the care and supervision that his medical conditions require, and Ms. Knight is simply not a certified home health aide.

130. After she was informed by G.S.'s case manager that FSSA might be willing to approve some reimbursement to her, even after July 1st, were she to become a certified home health aide, Ms. Knight began the process to attempt to obtain this certification. While the course allows her to take the required classes at her leisure, due to her responsibilities caring for G.S. (as well as her other children), Ms. Knight has had great difficulty finding time to even take a handful of these courses. By way of example, she has been forced to begin taking an hour-long class at 11:30pm or midnight but understandably has difficulty paying attention to the class at that late hour after a full day of caring for G.S. beginning early in the morning.

131. The online class that Ms. Knight is taking consists of a number of hour-long classes comprising four "parts." Due to all of these difficulties, she has thus far completed only 8 of 21 classes in one of these four parts. Not only is it virtually inconceivable that Ms. Knight will become certified as a home health aide prior to July 1st, but even adding this small amount of

coursework to her schedule has already had a negative impact on Ms. Knight's mental and physical health.

132. If FSSA's prohibition on Ms. Knight providing attendant care services to G.S. goes into effect on July 1st, in order to avoid having G.S. institutionalized, Ms. Knight would be forced to somehow return to work outside of the home in order to afford basic necessities for herself and her family. However, she has absolutely no idea how this might work. She has considered the option, for instance, of attempting to obtain a job for DoorDash or Uber Eats (or a similar service) and simply bringing G.S. with her while she is delivering food to customers. Not only would this deleteriously impact G.S.'s quality of life, but it would place his health and safety at great risk as he would be removed from his medical equipment and placed in an environment where it would be difficult if not impossible for his mother to monitor his condition.

133. Because she obviously cannot leave G.S. alone in order to return to work outside of the home, and because there are no other providers willing and able to provide care and supervision to G.S., Ms. Knight may have no option other than to seek an institutional placement for G.S. She has absolutely no idea how this would work and views it as her last option as she wants to do everything possible to ensure that G.S.'s quality of life does not suffer.

Concluding Factual Allegations

134. FSSA has failed in its duty under federal Medicaid law to ensure that the individual plaintiffs and IPAS's other constituents receive skilled services that are necessary to ensure that their medical needs are met and that they are able to continue residing safely and securely in the community.

135. FSSA receives federal financial assistance, and the defendants are therefore subject to the requirements of the Rehabilitation Act of 1973, 29 U.S.C. § 794.

136. As a result of the actions or inactions of the defendants, the individual plaintiffs and the other constituents of IPAS are suffering irreparable harm for which there is no adequate remedy at law.

137. At all times, the defendants have acted or refused to act under color of state law.

Legal Claims

138. The failure of FSSA to ensure that the individual plaintiffs and the other constituents of IPAS receive medically necessary skilled services—whether those services are provided as nursing services, preventive services, or some other form of "medical assistance" that must be covered under federal Medicaid law—violates 42 U.S.C. § 1396a(a)(8), 42 U.S.C. § 1396a(a)(10), and 42 U.S.C. § 1396a(a)(43). This claim is brought against the official-capacity defendants.

139. The prohibition on the receipt of attendant care services by A&D Waiver enrollees who receive structured family caregiving services results in a denial of medically necessary care in violation of 42 U.S.C. § 1396a(a)(10)(A) and 42 U.S.C. § 1396a(a)(43). This claim is brought against the official-capacity defendants.

140. If the changes to the A&D Waiver are allowed to take effect on July 1, 2024, the individual plaintiffs and the other constituents of IPAS will be placed at risk of institutionalization in violation of the "integration mandate" of the Americans with Disabilities Act of 1990 ("ADA") and the Rehabilitation Act of 1973 ("Rehabilitation Act"). The ADA claim is brought against the official-capacity defendants, and the Rehabilitation Act claim is brought against all defendants.

141. To the extent that attendant care services are deemed to be any service available under federal Medicaid law other than "personal care services," the prohibition on allowing LRIs to serve as providers of attendant care services violates the "free choice of provider" provision of federal Medicaid law, 42 U.S.C. § 1396a(a)(23). This claim is brought against the official-capacity

defendants.

Request for Relief

WHEREFORE, the plaintiffs respectfully request that this Court do the following:

1. Accept jurisdiction of this cause and set it for hearing.
2. Declare that the defendants have violated the rights of the plaintiffs for the reasons noted above.
3. Issue a preliminary injunction enjoining the defendants from prohibiting or otherwise restricting LRIs of enrollees in the A&D Waiver from serving as providers of attendant care services through that program, pending further order of the Court.
4. Issue a permanent injunction as necessary to remedy the legal violations noted above.
5. Award the plaintiffs their costs and attorneys' fees pursuant to 42 U.S.C. § 1988, 29 U.S.C. § 794a(b), and/or 42 U.S.C. § 12133.
6. Award all other proper relief.

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