

IN THE UNITED STATES DISTRICT COURT  
FOR THE MIDDLE DISTRICT OF LOUISIANA

BRYAN STEIN, by his parents and guardians,  
ROBERT and MELANIE STEIN,

Plaintiff

v.

Civ. Action No.

ALAN LEVINE, Secretary  
Louisiana Department of Health and Hospitals,  
in his official capacity;

KATHY KLIEBERT , Director,  
Office for Citizens with Developmental Disabilities,  
Louisiana Department of Health and Hospitals,  
in her official capacity;

EASTER SEALS LOUISIANA;

KATHLEEN LINER,

Defendants

**COMPLAINT**

**I. PRELIMINARY STATEMENT**

1. This is a civil rights lawsuit by BRYAN STEIN, a 38 year old man who lives in his own home in Franklinton, Louisiana. His life and health are threatened by the arbitrary action of Louisiana state officials, and their agents, to drastically reduce the services which enable him to live in his own home. He has been told that his support staff hours will be cut from twenty-four hours a day (168 hours per week) to about 3 to 7 hours a day (20 to 50 hours per week). His pleas to Secretary Levine and other state officials for an explanation have been unavailing.

2. Solely as a cost-cutting move, Defendants are applying a generic assessment instrument arbitrarily and in a manner for which the instrument is unsuited. Defendants have not provided notice and an explanation of an established procedure and standards which would allow for exceptions to the individual service cuts, so individuals such as BRYAN STEIN cannot fairly be expected to utilize that exceptions procedure.
3. BRYAN STEIN receives individual support staff services which are essential to his care, health and safety and his ability to participate in community life. Mr. Stein is a person with profound intellectual and developmental disabilities. The services are provided by the State of Louisiana under the federal-state Medicaid program through what is called the Now Opportunities Waiver.
4. But for these services Mr. Stein would be compelled to return to a large congregate state institution. He lived for 22 years at the Hammond Developmental Center, one such congregate state institution, and during that time he was abused by staff, assaulted, and repeatedly injured.
5. Defendant state officials have established a “resource allocation” system to assess the needs of participants in the NOW Waiver and, then, to determine the level of need and resulting hours of service which the person may receive. The assessment system involves use of a Supports Intensity Scale (SIS) which is to be administered by a trained professional together with the participant, support agency staff and the parents or guardian of the person, who provide the information input into the SIS report. This resource allocation system was explicitly premised on the Defendant state officials’ desire and plan to reduce

support services provided to Louisiana citizens with developmental disabilities and to cut the budget for such services.

6. Defendant state officials have permitted their agents to administer the SIS in an arbitrary and damaging manner, resulting in assignment of Plaintiff STEIN to the lowest level of need and, therefore, the lowest level of staffing.
7. Plaintiff STEIN currently receives 24 hour a day full-time support staffing on account of his intense level of support needs, his frequent myclonic seizures, and the risk to him and others due to involuntary falling and striking out during seizures.
8. At the lowest level of need under the SIS, Plaintiff STEIN would receive only 30 to 50 hours of service weekly, not the 168 hours weekly he now receives. This reduction would result in risk of serious physical harm and death to Plaintiff Stein, injuries to other individuals, and a denial of the services mandated by the United States through the Medicaid-funder and regulated NOW Waiver.
9. Acting under color of state law, and on behalf of the state defendants, Defendants EASTER SEALS LOUISIANA and KATHLEEN LINER administered the state defendants' scale in an arbitrary manner, inserting false information into the assessment, and creating various versions of the results for Plaintiff Stein, all resulting in the risk of serious physical harm and death to Plaintiff Stein, injuries to other individuals, and a denial of the services mandated by the United States through the Medicaid-funder and regulated NOW Waiver.
10. Defendants have violated BRYAN STEIN's right to due process of law under the Due Process Clause of the Fourteenth Amendment to the Constitution of the

United States, his right to be free from unnecessary institutionalization under that Clause, and his rights under the Americans with Disabilities Act, and the Medicaid Act.

11. Plaintiff seeks declaratory and injunctive relief from all defendants mandating a fair assessment of his needs, and continued provision of the services and staffing which he now receives, and an end to the arbitrary cutbacks in services and staffing which Defendants, solely to reduce their budget, but in violation of the law, have been committed.

## **II. PARTIES**

12. Plaintiff BRYAN STEIN is 38 years old and lives at 1004 Carter Street, Franklinton, Louisiana 70438, in a small bungalow. He sues by his parents and guardians, Robert and Melanie Stein, who live at P.O. Box 479, Robert, Louisiana 70455. He is a person with profound mental retardation, and a seizure disorder, and West's Syndrome. His birth date is October 4, 1971. xx
13. Defendant LOUISIANA DEPARTMENT OF HEALTH & HOSPITALS, ("the DEPARTMENT") is the state agency which administers the federal-state Medicaid program called the NOW Waiver which is a subject of this Complaint. The Department's address is 628 N. 4th Street, Baton Rouge, LA 70802.
14. Defendant ALAN LEVINE is Secretary of the LOUISIANA DEPARTMENT OF HEALTH & HOSPITALS and is sued in his official capacity.
15. Defendant KATHY KLIEBERT is Director of the Office for Citizens with Developmental Disabilities of the LOUISIANA DEPARTMENT OF HEALTH &

HOSPITALS and is sued in her official capacity. She reports to Defendant LEVINE and is under his supervision.

16. In this Complaint, Defendants DEPARTMENT, LEVINE and KLIEBERT are sometimes referred to as the “Defendant state officials” or the “Defendant state agency” or the “state agency Defendants.”

17. Defendant EASTER SEALS LOUISIANA, with regard to all actions and omissions and policies and practices under this Complaint, is an agent of the Defendants DEPARTMENT, LEVINE and KLIEBERT. EASTER SEALS LOUISIANA is also responsible for all actions and omissions and policies and practices of Defendant LINER. It is located at 19405 Helenberg Rd, STE 1, Covington, LA 70433, 985-892-7604.

18. Defendant KATHLEEN LINER is a Supports Coordination Supervisor, for EASTER SEALS LOUISIANA, 19405 Helenberg Rd, STE 1, Covington, LA 70433, 985-892-7604.

### **III. JURISDICTION**

19. This Court has jurisdiction over this matter 42 U.S.C. §§ 1983 and 1988, and 28 U.S.C. §1331 (federal question jurisdiction) and 1343 (civil rights jurisdiction).

20. This action arises under the Fourteenth Amendment, the Medicaid Act (42 U.S.C. § 1396, 1396a and 42 U.S.C. § 1315), the Americans with Disabilities Act (Title II, 42 U.S.C. § 12132, all other provisions of the ADA, as amended, and its implementing regulations including but not limited to 28 C.F.R. § 35.130(d) and 28 C.F.R. § 35.130(b)(7)).

21. Defendants LEVINE, KLIEBERT , EASTER SEALS LOUISIANA and LINER have each acted under color of state law in depriving Plaintiff BRYAN STEIN of his rights as set forth herein.
22. As to injunctive relief, an action at law is not adequate and will not provide full relief.
23. Venue is appropriate in this Court because, among other reasons, the Defendant state agencies and individual state official defendants are located in this District, the NOW Waiver program in question is administered through this agency in this District, and the other defendants, EASTER SEALS LOUISIANA and KATHLEEN LINER, do business in this District.

#### **IV. STATEMENT OF FACTS**

##### **A. BRYAN STEIN Lives in the Community**

24. Plaintiff Stein lives in his own home. He enjoys his big lounge chair and his large bed with his soft pillows his privacy at bath time. His room is decorated with his quilt pictures of his family. He spends part of each weekday at the day program operated by Franklinton Association for Challenged Citizens. However, due to his seizures and his functional level, his habilitation needs, and the need to keep him safe, Bryan goes to the center each day for socialization skills and other activities, and is accompanied by his caregiver at all times. Evenings, he listens to music and takes daily rides with staff. He also goes to Wal-Mart, the grocery to get milk and other food, and to do personal errands. In all these activities, and twenty-four hours a day, Plaintiff Stein is supervised by staff from Franklinton.

25. Plaintiff Stein has a developmental disability, namely, profound mental retardation, West's syndrome, and a seizure disorder. BRYAN STEIN became a person with mental retardation after a virus caused a fever when he was eleven months old. West's syndrome is a serious epileptic syndrome which usually begins in the first year of life. It involves seizures known at that point in time as "infantile spasms." West's syndrome can be considered the classic disorder of the catastrophic childhood epilepsies. It was identified 160 years ago. The evaluation and treatment of the disease are complex.
26. Plaintiff Stein's seizures are dramatic and need to be attended to without delay to protect his life and health. He experiences auras daily. He has about 15 to 20 seizures per month. His seizures are accompanied by screaming, hitting his head on the wall, or turning himself in circles, or other behavioral manifestations which are dangerous.
27. The seizures cause him to rapidly fall, with a consequent risk of serious injury to him. Falls or his striking out during a seizure also risk serious injury to others in the vicinity. The seizures may occur any time of day or night. Only staff (or family) familiar with the subtle precursor indications can prevent or mitigate the effect of such falls. If he is not accompanied at all times by a trained person, he is at risk of death resulting from a fall which injures him or from falling or becoming incapacitated in a dangerous circumstance, such as a road.
28. Plaintiff Stein's quality life in the community is funded by the State of Louisiana through a Medicaid Waiver program called the "New Opportunities Waiver," also often called the "NOW Waiver." The NOW Waiver, funded by the State with

federal financial participation, is described further below. Overall, the NOW Waiver permits the State to serve people in the community at a lower cost than would otherwise be paid for congregate institutional care. By bringing down federal funds, the State saves additional money.

29. But for the community living provided by the NOW Waiver, Plaintiff Stein would be living in a large congregate institution for people with mental retardation. Indeed, under federal law, one cannot qualify for community services under the NOW Waiver – and the State of Louisiana cannot provide for such services under the NOW Waiver – unless one would otherwise be institutionalized.

**B. Hammond Developmental Center**

30. BRYAN STEIN’s life today is quite different than it had been for decades in prior State custody.
31. When BRYAN STEIN was 6 years old, his parents sought assistance from the State of Louisiana for his care. The only option offered by the State at that time was the Hammond Developmental Center. He therefore became a resident of Hammond.
32. During the 22 years BRYAN STEIN was confined to the Hammond Developmental Center, he was severely and repeatedly victimized and injured. At various times, he was subjected to such harms as biting by other clients, physical abuse by a staff person who was caught hitting him in the head, broken hand, broken feet, head surgery for removal of scar tissue due to numerous of falls. At Hammond, he was required to wear a helmet to help protect his head in case of a

fall due to a seizure. His parents continually sought action by the State to protect their son.

33. Hammond established a routine of enemas following seizures. These were done in such a fashion as to cause him serious physical injury, resulting in the necessity of surgical repair.
34. The unremedied violence and lack of elementary care at the Hammond institution highlights the urgency of BRYAN STEIN's move to the community.

### **C. Plaintiff's Own Home**

35. After about 22 years at the Hammond institution, and with the recommendation and support of the State of Louisiana, Plaintiff Stein moved into a home with a roommate. This home did not work for Mr. Stein as there were open space heaters and with his seizure activity this was dangerous.
36. Six months later after his initial placement, Bryan moved into a home that was bought by his parents. His roommate moved with him. This was short lived as Bryan could not, and cannot, understand boundaries nor does he have the mental capacity to understand co-habitation. Also, because support staff need to be focused on Mr. Stein on account of his seizures, having another resident in the home, whose needs might distract from Mr. Stein's, creates undue risk for Mr. Stein and the other resident.
37. The new home enabled Mr. Stein to live safely in the community, and to receive training and habilitation, all with the support of the State of Louisiana's NOW Waiver Program for in-home supports through the Franklinton Association for Challenged Citizens.

#### **D. New Opportunities Waiver (“NOW Waiver”)**

38. In 1971, an amendment to the Social Security Act allowed the financing of special facilities with federal dollars under the Medicaid program. These facilities were called Intermediate Care Facilities for the Mentally Retarded or ICFs/MR. As of 2007 Louisiana defined ICFs/MR as Intermediate Care Facilities for People with Developmental Disabilities or ICFs/DD. The purpose of the ICF/DD is that of diagnosis, treatment, or rehabilitation of people with developmental disabilities. The ICF/DD provides a protected residential setting, ongoing evaluation, planning, 24-hour supervision, coordination, and integration of health or rehabilitative services that are individualized according to each participant’s needs. ICF/DD services are provided in a broad range of residential services such as community homes (up to 7 people), group homes (8-15 people), small (16-32 people) or large (33+) institutions, including state-operated supports and services centers (previously developmental centers) and privately-operated agencies.
39. Federal law permits a “waiver” of certain ICF/MR requirements for services and programs which permit people with disabilities to live vital lives in the community. Such opportunities, funded with state and federal dollars, are provided under what is called the Home and Community-Based Services Waiver. In Louisiana, one such “waiver” is the New Opportunities Waiver.
40. The New Opportunities Waiver is a Home and Community-Based Services Waiver program. Waiver programs are based on federal criteria which allow services to be provided in a home or community-based setting for the participant who would otherwise require institutional care. Due to the demand for these

services, there is a Developmental Disability (DD) Request for Services Registry (RFSR) that lists participants who meet the Louisiana definition of developmental disability and their request date. This waiver is offered on a first-come, first-served basis.

41. The New Opportunities Waiver (NOW) is only appropriate for those participants whose health and welfare can be assured through the Comprehensive Plan of Care and for whom home and community-based waiver services represent a least restrictive treatment alternative. NOW is intended to provide specific, activity-focused services rather than continuous custodial care.
42. The Comprehensive Plan of Care is an individual support plan which describes the person's needs, services to be provided, staffing, placement, objectives for their services, and additional information.
43. The following are the services provided under the NOW: Individualized and Family Support (IFS) Service-Day-Night; Center-Based Respite; Community Integration and Development; Environmental Accessibilities Adaptations; Specialized Medical Equipment and Supplies as an Extended State Plan Service; Supported Living; Substitute Family Care; Day Habilitation and Transportation for Day Habilitation; Supported Employment and Transportation for Supported Employment; Employment Related Training; Professional Services; Personal Emergency Response System; Skilled Nursing Services; and One-Time Transitional Services.

44. One is not eligible to request or receive placement in the NOW Waiver unless one meets the requirements for institutional facility level of care for medical and/or psychological criteria.
45. As examples of what is provided under the NOW Waiver to Mr. Stein, Day Habilitation services provide participants with assistance in developing social and adaptive skills necessary to enable them to participate as independently as possible in the community. It allows for peer interaction, meaningful and age-appropriate activities, community and social integration, which provide enrichment and promote wellness. It includes the assistance and/or training in the performance of tasks related to acquiring, maintaining, or improving skills including but not limited to: personal grooming; housekeeping; laundry; cooking; shopping; and money management. In addition, Day Habilitation services may serve to reinforce skills or lessons taught in school, therapy, or other settings.
46. Employment Related Training services consists of paid employment for participants for whom competitive employment at or above the minimum wage is unlikely and who because of their disabilities need intensive ongoing support to perform in a work setting. Employment Related Training services also include training designed to improve and/or maintain the participant's capacity to perform productive work and function adaptively in the work environment.
47. Supported Living services assist participants to acquire, improve, or maintain social and adaptive skills necessary to enable participants to reside in the community and to participate as independently as possible. Such services include assistance and/or training in the performance of tasks such as personal grooming,

housekeeping, and money management (including bill paying). These services will also assist the participant in obtaining financial aid, housing, advocacy and self-advocacy training as appropriate, emergency support, trained staff, and assisting the participant in accessing other programs for which he/she qualifies.

#### **E. Process Under the NOW Waiver**

48. Louisiana has established a “person-centered” planning process for the NOW Waiver.
49. The process for planning and providing supports to NOW Waiver participants, including Mr. Stein, involves a) the discovery of information regarding his interests, goals and support needs, b) the use of the information to develop a support plan which includes strategies to assist in achieving the participant’s goals and address his/her support needs, c) implementation of the plan including training for the person’s family and support staff, and securing of needed resources, and d) periodic review to assess if implementation has occurred and positive changes are resulting from the plan.
50. Among the values established by the State of Louisiana for the NOW Waiver, and mandated as the basis for it, is that the planning process “builds on the important, meaningful life experiences of the person rather than with the limitation of services actually available,” and that there is “a partnership with the person and all the important people in his/her life.”
51. The Louisiana Resource Allocation System is completed as part of a person-centered planning process. As a part of the planning process, the support team assists the participant in determining needed supports and services including

recommended Individual and Family Supports (IFS) under the NOW to achieve the person's life vision and goals. The support team completes this process using the framework in a document called, "Guidelines for Support Planning." IFS may also be referred to as attendant care services (ACS).

52. These guidelines provide for the allocation of IFS supports based on the assessment of participant needs. For adults, OCDD has selected the Support Intensity Scale (SIS), complemented by the Louisiana Plus (LA PLUS), for assessing persons' support needs.
53. IFS support hours are offered to participants based on the Louisiana Resource Allocation System. This system provides for the allocation of IFS hours to participants based on one of seven levels of need. The system distinguishes participants living with family and those living independently.

#### **F. The Support Intensity Scale**

54. The "Support Intensity Scale" ("SIS") is a tool to evaluate the needs for services of individuals served by the NOW Waiver. The SIS was developed and released in 2004 by the American Association on Intellectual and Developmental Disabilities.
55. The SIS was not developed to be a tool for computing hours of support staff or for decision-making on whether to cut people from needed services.
56. The Support Intensity Scale is an assessment instrument intended to assist in identifying a person's support needs. An assessment of the person's pattern and intensity of support needs is essential to the development of person-centered plans for providing supports. The primary purpose for providing supports to persons

- with intellectual disabilities is to enhance human functioning and personal outcomes.
57. A basis for the Support Intensity Scale is the principle that individualized supports should be provided in natural environments and based on the principles of equity and inclusion.
58. The intensity of a person's support needs reflects an enduring characteristic of the person rather than simply a point in time description of the need for a particular type of support.
59. Support needs refer to the pattern and intensity of supports necessary for a person to participate in activities linked to normative human functioning. Supports are resources and strategies that aim to promote the development, education, interests, and personal well-being of a person and that enhance individual functioning.
60. The Support Intensity Scale measures a person's general supports needs and produces a number of scores. It identifies medical and behavior problems, and also includes basic support need areas like: a) Home Living Activities, b) Community Living Activities, and c) Health and Safety Activities. The "SIS ABE" refers to the sum of the scores for these 3 areas that have been found useful in helping resource allocation.
61. Given the importance of administration of the Support Intensity Scale, it is essential that the interviewer have solid interviewing skills. The data which is input into the scale scoring must be based on interview with the person and with others who know the person.

62. Budget allocations for states adopting the Supports Intensity Scale approach can be made on a “Level Budget Allocation,” setting numbered “levels” with each assigned a dollar amount, or an “Individual Budget Allocation,” where the dollar amount is tied to the needs of the individual and the individual decides how to use the full amount.
63. “[T]he field is moving toward individualized budgets,” according to Louisiana’s consultant on these issues. However, Louisiana has chosen to assign individuals to broad “levels,” under a Level Budget Allocation, and not to tie budgets to individual budget needs.
64. Ignoring individual needs in this way requires that a mechanism be established to adjust the broad “level” calculated under the SIS to the person’s specific situation. Otherwise, the person-based mandate under the Waiver would not be satisfied.
65. Regardless of the method utilized, it is important that an “exceptions protocol” be developed. To ensure that budget models accommodate individuals with exceptional needs and related costs, the state must develop a process which, generally, provides for adjustments to the budget allocations which the budget allocation system might otherwise provide. For example, such a process would include these steps:
- a. Identify and separate individuals who need and cost more.
  - b. Develop rules and procedures and designate staff to handle the process for adjusting or making exceptions.
  - c. Develop waiver safeguards that come into play when the amount of the limit is insufficient to meet needs.
  - d. Convene a committee to review individuals who do not fit within the model.
  - e. Adjust budget allocations to raise or lower amounts, as needed.
  - f. Decide to leave high allocations unchanged, after review.

- g. Remove any individual deemed to have extraordinary needs and associated costs from the budget model.

#### **G. Person-Centered Process**

- 66. Under the NOW Waiver, each person's typical weekly schedule must be individualized in a person-centered planning process.
- 67. The "levels" established by OCDD start at Level 1A, representing the lowest level of needs, and extend to Level 6, representing the highest level of need. The information on the SIS/LA PLUS is used both in determining the level membership in the Resource Allocation System and in developing support plans for each participant based upon their unique support needs.
- 68. The Louisiana-determined "levels" were established through statistical analyses and model fitting of assessment data gathered during a sampling of NOW waiver participants in 2006 and 2007, and review of services and associated costs for FY 2006 and 2007 for these same participants.
- 69. The "level" system, by its nature and its statistical origin, does not establish what is needed for each person under the Medicaid Waiver rules or under an individualized plan of care. The assigned level is a starting point and it must then be adjusted, if needed, to ensure that individual needs are met.
- 70. Louisiana recognizes that assignment of a "level" is not the conclusion of the determination of the resources required for an individual in the NOW Waiver program. OCDD recognizes that the resource allocation system must make accommodations for participants with atypical or specialized needs in order to be responsive to all service recipients; certain people have unique needs that must be

addressed outside the OCDD guidelines. Additional hours, OCDD mandates, may be required “both temporarily and on a permanent basis.”

71. Among the reasons for additional hours of in-home support recognized by Louisiana are three, all of which apply to Plaintiff BRYAN STEIN. These reasons include when sharing is not advisable, where the person has a significant behavioral issue, and where a person requires extensive physical assistance to participate in most home and community activities.

#### **H. Plaintiff’s Planning Under the NOW Waiver**

72. Mr. Stein is provided what is called “Supports Coordination” under the NOW Waiver. This coordination is provided by Defendant EASTER SEALS LOUISIANA, under an agreement with, and funding by, the State of Louisiana. EASTER SEALS LOUISIANA is responsible for the administration of the Supports Intensity Scale interview under the NOW Waiver, and for coordination and monitoring of the plan of care required by the Waiver, and is and was responsible for the administration of the SIS for BRYAN STEIN.

73. EASTER SEALS LOUISIANA is also responsible for coordinating Plaintiff’s services, ensuring that his Comprehensive Plan of Care is implemented, and for advocating for him to ensure that his needs are met under the Waiver.

74. Mr. Stein’s staff support services under the Waiver are provided by Franklinton Association for Challenged Citizens, Supported Independent Living Program, P.O. Box 622. Franklinton, LA 70438. The Association is identified as “FAAC” in this Complaint.

75. The interviewer for the administration of the SIS was KATHLEEN LINER, a Supports Coordination Supervisor for Easter Seals Louisiana. Ms. Liner was not the Case Manager for Mr. Stein and was not familiar with the details of his situation.
76. Defendant LINER completed the SIS for Mr. Stein on or about July 21, 2009.
77. Present at his home for the administration of the SIS for Mr. STEIN, were Defendant LINER for Defendant EASTER SEALS LOUISIANA, Pam Magree and Tara Jones for FAAC, Melanie Stein, Plaintiff's mother, and Mr. STEIN. Mr. STEIN is non-verbal and otherwise disabled as described elsewhere in this Complaint.
78. The SIS is a 13 page document with many dozens of check offs, questions, and choices to be made. It rates support needs in activity subscales called Home, Community, Lifelong, Employment, Health and Safety, and Social. The SIS process requires that the interviewer (here, Defendant LINER) take substantial time obtaining information from those identified "respondents" who are those individuals who know the NOW Waiver participant, that is, Mr. Stein. The interviewer may not make guesses or make entries into the document without having information on which to base particular entries into the form.
79. Completing a SIS requires discussion and interaction and typically can take hours.
80. Mr. Stein's mother questioned Defendant LINER when it became clear that LINER had very little knowledge of PLAINTIFF STEIN's needs or circumstances, and stated that LINER was consequently administering the SIS without a factual context regarding BRYAN STEIN. On being questioned,

Defendant LINER, without completing the SIS or completing the meeting, abruptly left the meeting and left the home, shutting down the meeting, and stating that she would complete the SIS at her office. LINER stated, “Fine, I really know how to finish this evaluation.” The “meeting” lasted just 20 minutes. The SIS process had barely begun.

81. Although each is dated the same date within the form, July 21, 2009, Defendants LINER for Defendant EASTER SEALS LOUISIANA completed not one, but three, SIS evaluation forms, none of which was completed with the input and participation of Mr. Stein’s mother, Melanie Stein, and two of which bear later handwritten dates at the top of their front pages.
82. There is no provision in the Defendant state officials’ policies or protocols for multiple SIS evaluations to be completed, all with the same date, and none with the participation of the respondents named in the SIS evaluation.
83. The three SIS evaluations have widely and profoundly different information on critical points, and demonstrate an essentially arbitrary and ill-informed process by Defendants LINER for Defendant EASTER SEALS LOUISIANA.
84. Version 1. SIS Version 1 was completed on or near the July 21, 2009 meeting date. It concludes that Mr. Stein has a SIS Support Needs Index of 54, and Percentile Support Needs Index of 1. This percentile of 1, according to the OCDD Level standards, would mean that Mr. Stein has “minimal” support needs, would

be expected to have “mild intellectual disabilities” and be able generally to be independent.<sup>1</sup>

85. Version 2. At some point, Defendants LINER for Defendant EASTER SEALS LOUISIANA, or others on behalf of the Defendant state officials, modified the SIS without input or participation of Mr. Stein or his guardians, or the other participants identified as respondents in the SIS evaluation. This second version is marked in handwriting “Correction 9/09.” This version concludes that Mr. Stein has a SIS Support Needs Index of 100, and Percentile Support Needs Index of 50.

86. Version 3. At some later point, Defendants LINER for Defendant EASTER SEALS LOUISIANA, or others on behalf of Defendant state officials, again modified the SIS, again doing so without input or participation of Mr. Stein or his guardians, or the other participants identified as respondents in the SIS evaluation. This third version is marked in handwriting “Corrections 12/15/09.” This version concludes (as did Version 2) that Mr. Stein has a SIS Support Needs Index of 100, and Percentile Support Needs Index of 50.

87. Each version includes some incorrect information. For example, each states that Mr. Stein may be left unsupervised “less than 1” hour per day. In fact, he can never be left unsupervised due to the extreme danger from his seizures. Each

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<sup>1</sup> This is the OCDD description of Level 1: “Members of Level 1A, with regard to our citizens with developmental disabilities, require the least amount of supports. These participants have SIS scores below the 25th percentile indicating fewer General Support needs (Home Life, Community, Health and Safety Support Needs) than 75% of the population with developmental disabilities. Support needs tend to be minimal. Most members have mild intellectual disabilities. They are capable of managing many aspects of their lives independently. Teaching supports and monitoring, as well as supports of a more intermittent nature, are frequently what are requested by 1A members.”

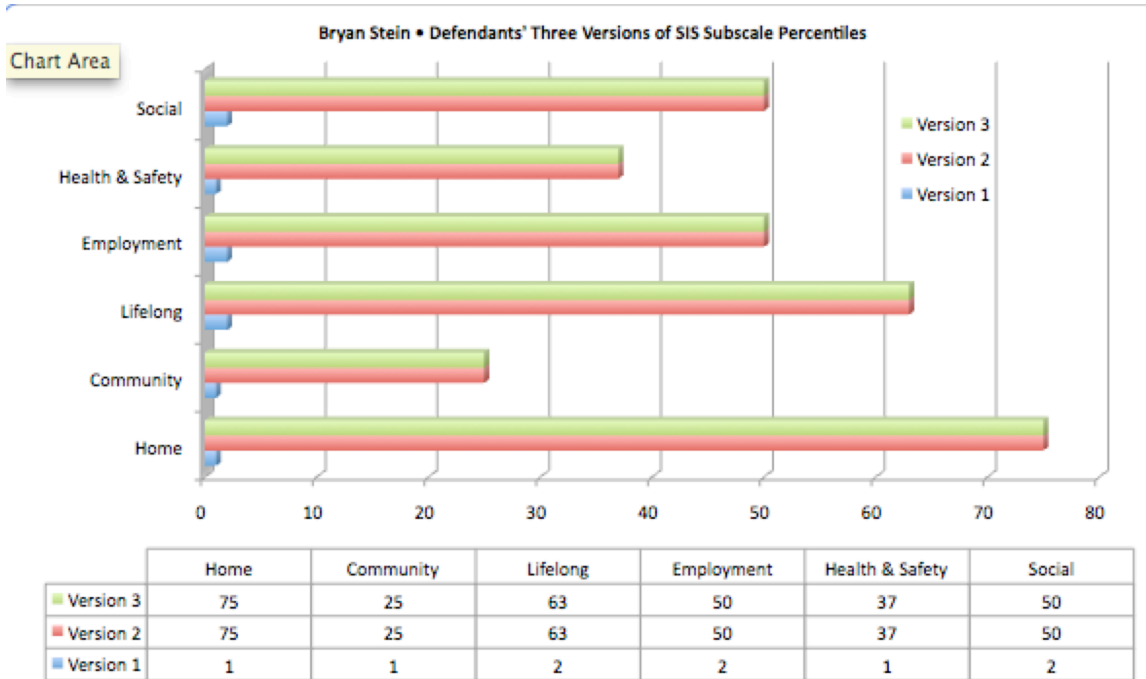
- version states that he has no difficult sleeping at night. In fact, his seizures can occur at night.
88. The 50<sup>th</sup> Percentile (in Versions 2 and 3) would put Mr. Bryan in a category of persons with significant support needs and severe or profound intellectual disabilities.<sup>2</sup>
89. An accurately performed SIS assessment would result in documentation of significantly more intense support needs than that shown in the three versions produced by Defendants.
90. Version 1's section titled "Comments/Notes" was one paragraph (5 lines) long and described Mr. Stein's seizures and seizure-related facts.
91. Versions 2 and 3 – again without involvement or input of the guardian, his mother, or the other participants identified as respondents in the SIS evaluation, added 3 paragraphs (total 7 lines) including false and derogatory statements about Mr. Stein's mother.<sup>3</sup>
92. Each of the three SIS versions has is marked by Defendants LINER for Defendant EASTER SEALS LOUISIANA as "DATE SIS COMPLETED" "July 21, 2009."
93. The arbitrariness and lack of reliability and dependability of the three SIS assessments is illustrated by the specific subscale percentile ratings on the activity

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<sup>2</sup> Level 2, per OCDD, is described: "Members of Level 2 have General Support Needs that place them between the 50th and 75th percentile relative to other persons with developmental disabilities. These participants have significant support needs relative to tasks of daily living. Most participants in Level 2 have severe or profound intellectual disabilities. For most, behavior and medical support needs are minimal or nonexistent." Level 1 B goes from 25% to 50% but does not apply to Mr. Stein as he does not have "mild" disabilities.

<sup>3</sup> The added language calls Mr. Stein's mother and his seizures "obstacles" to sharing services, asserts falsely that "[h]is mother bought him a house so that he will not have to share" and falsely that "Mom gives Bryan Valium occasionally when he is agitated."

subscales. Version 1 purports to describe a quite different person than Versions 2 and 3, although each is claimed by DEFENDANTS EASTER SEALS LOUISIANA and LINER to be BRYAN STEIN.



94. After the July 21, 2009 SIS administration was completed, Mr. Stein, through his parents, was informed by Judy Vellarrubia, Case Manager at Defendant EASTER SEALS LOUISIANA, about October 12, 2009, orally that he scored at a Level 1 on the SIS and that, therefore, at Level 1, he would be denied nearly all of the individual support staff hours he requires; the result of such a denial would be that he would be forced to leave his home and be institutionalized.

95. This information from EASTER SEALS LOUISIANA was catastrophic. The termination of the essential support staffing, the re-institutionalization, and the trauma threatened will – unless reversed – result in an end to BRYAN STEIN’s

valued community life, denial of his Medicaid-mandated services, and great distress to him.

96. A subordinate official of the Defendant state officials, during that same week, (when the family demanded an explanation) told Mr. Stein, through his parents, over the telephone, orally and unofficially that the Level 1 determination was a “mistake.” However, Defendant state officials have never confirmed that this statement despite Mr. Stein’s parents explicitly, repeatedly, and in writing seeking to confirm that he would not be denied staffing support hours and that the Level 1 determination by Defendants LINER for Defendant EASTER SEALS LOUISIANA was inoperative.

97. The only official notification from the Defendants was that received about October 12, 2009 that BRYAN STEIN’s SIS Level was Level 1 and that his staff support would therefore be cut to that permitted under Level 1. Level 1 staffing would be about 30 to 50 hours per week, not the 168 hours he currently receives.

98. Mr. Stein, through his parents, did not learn the discrepant and arbitrary SIS results until December 17, 2009.

99. The consequence of the reduction to Level 1 would be that, rather than full-time, 23 hour per day care and supervision, Mr. Stein would receive no more than 30 to 50 hours a week in individualized care and supervision, thus putting him at risk of serious injury or death, and putting others at risk who may be near and about when he has a seizure. The communications from Defendants have caused extreme emotional distress and suffering to the parents of BRYAN STEIN, and disruption in the planful administration of his program and services.

**I. Communications to the Governor, Secretary Levine and Director Kathy Kliebert**

100. Mr. Stein, through his parents, communicated the urgency of the situation and the injustice of the SIS assessment directly to the Governor, Bobby Jindal. Governor Jindal's Director of Constituent Services, Ragan Dickens, who wrote back, "Rest assured that your concerns are of great importance to the Governor." Mr. Dickens forwarded the correspondence to the Department of Health and Hospitals. The letter to the Governor was substantially the same as that quoted below which was sent to Secretary Levine.

101. Mr. Stein, through his parents, communicated the urgency of the situation and the injustice of the SIS assessment directly to Defendant ALAN LEVINE, Secretary of the Department of Health and Hospitals. They wrote on November 12, 2009:

To: Alan Levine

I'm writing to request, in writing, the criteria use by your Team to determine the '1 rating' given to my son, BRYAN STEIN, which than equated to 30 – 50 hours a week individualized care. In addition, provide the name and qualifications of the individual who visited with and completed Bryan's evaluation form used by such Team and the qualifications and names of each Team member. Lastly, provide copies of any documents not mentioned that was used by the Team, persons or subsequent teams not already identified, who rendered the life alternating decision imposed on Bryan.

Briefly, Bryan is 38 years old, mentally challenged (18 month old level) with a sever seizure disorder. Bryan is non-verbal, ambulatory, but cannot function on his own, he require 24/7 care. For 25 + years Bryan was a resident of Hammond Developmental Center (HDC) where he incurred numerous sever injuries do to the client care ratio which was at best 6:1 on the day shift and 17:1 on nights. Bryan was physically abused while at HDC; Bryan had NO quality of life. All those years our son was in HDC we fought for "something better", and along came the Now Wavier Program, promoting itself as an opportunity for a better "quality of life".

“Not to worry about funding” says Waiver’s promoters, “this program is far less expensive for the State and monies will always be there for that very reason”.

For the past 10 years Bryan's quality of life HAS improved a hundred fold, NO injuries, and he no longer wears a seizure helmet 24 hours a day!! Why this dramatic improvement? Because for the first time in his life, he had the one on one care and attention so absolutely necessary to achieve these results.

So what is the issue? The process used to decide care! A State worker was sent out to complete a 'form' which was then 'evaluated' by a 'team' who NEVER laid eye's on my son, did not consult with his care provider nor parents and concluded that he requires only 30 to 50 hours a week care!!!! This is not only illegal but also immoral.

The safety and quality of Bryan’s life should out weigh any budget cuts. The process use to determine his care fell well short of his needs.

102. Mr. Stein, through his parents, communicated the urgency of the situation and the injustice of the SIS assessment directly to Defendant KATHY KLIEBERT , Director, Office for Citizens with Developmental Disabilities, Louisiana Department of Health and Hospitals. They wrote to her on November 12, 2009 in language substantially the same as that quoted below which was sent to Secretary Levine

## **CAUSES OF ACTION**

### **First Cause of Action – Due Process of Law, Procedural Fairness**

103. All the preceding allegations are hereby incorporated as if fully set forth herein.
104. The assessment system established and administered by Defendants LEVINE and KLIEBERT , which utilizes the SIS assessment, and as administered by the agents of said Defendants, results in arbitrary and incorrect

assessments and decisions regarding the support staffing needs of individuals served by the NOW Waiver.

105. As applied to Plaintiff BRYAN STEIN, the assessment system established and administered by Defendants LEVINE and KLIEBERT , which utilizes the SIS assessment, and as administered by the agents of said Defendants, resulted in arbitrary and incorrect assessments and decisions regarding the support staffing needs of individuals served by the NOW Waiver. The EASTER SEALS LOUISIANA and KATHLEEN LINER multiple and incorrect assessments resulted in conclusions regarding his support needs which would deny BRYAN STEIN essential services and which would risk serious harm and death to him and to others.

106. Defendants failed to administer the system in a fair and uniformly applied manner, and in a manner and with an instrument designed to result in accurate and fair results. This has caused harm to BRYAN STEIN.

107. All Defendants have violated Plaintiff BRYAN STEIN's right to not be deprived of life, liberty or property under the Due Process Clause of the Fourteenth Amendment to the United States Constitution.

**Second Cause of Action - Due Process of Law, Unnecessary Institutionalization**

97. All the preceding allegations are hereby incorporated as if fully set forth herein.

98. The assessment system established and administered by Defendants LEVINE and KLIEBERT , which utilizes the SIS assessment, and as administered by the agents of said Defendants, results in arbitrary and incorrect assessments and decisions regarding the support staffing needs of individuals served by the NOW Waiver.

99. As applied to Plaintiff BRYAN STEIN, the assessment system established and administered by Defendants LEVINE and KLIEBERT , which utilizes the SIS assessment, and as administered by the agents of said Defendants, resulted in arbitrary and incorrect assessments and decisions regarding the support staffing needs of individuals served by the NOW Waiver. The EASTER SEALS LOUISIANA and KATHLEEN LINER multiple and incorrect assessments resulted in conclusions regarding his support needs which would deny BRYAN STEIN essential services and which would risk serious harm and death to him and to others.

100. All Defendants have violated Plaintiff BRYAN STEIN's right to not be deprived of liberty under the Due Process Clause of the Fourteenth Amendment to the United States Constitution in that their actions have caused a real and imminent risk of his being compelled to be institutionalized and deprived of liberty.

### **Third Cause of Action – Americans with Disabilities Act**

101. Plaintiff BRYAN STEIN (1) is an individual with a disability; (2) is otherwise qualified to participate in or receive the benefit of the Defendants' services, programs, or activities; (3) was excluded from participation in or denied the benefits of the public entity's services, programs, or activities, and was otherwise discriminated against by the public entities; and (4) such exclusion, denial of benefits, or discrimination was by reason of his disability.

<sup>102.</sup> In *Olmstead v. L.C.*, 527 U.S. 581 (1999), the United States Supreme Court held that Title II of the Americans with Disabilities Act of 1990 (ADA)

requires the placement of persons with mental disabilities in community settings, rather than in institutions, when: (1) the state's treatment professionals determine that such a placement is appropriate, (2) the transfer is not opposed by the individual, and (3) the placement can be reasonably accommodated given the resources available to the state and its obligation to provide for the needs of others with mental disabilities. A five justice majority held that a failure to provide care for individuals with mental disabilities in the most integrated setting appropriate to their needs may be viewed as discrimination, in violation of the ADA, unless the state or other public entity can demonstrate an inability to provide less restrictive care without “fundamentally altering” the nature of its programs.

101. Congress passed the Americans with Disabilities Act in 1990, 42 U.S.C. §§ 12101-12213, as amended. Designed as a comprehensive statutory scheme, the ADA seeks to eliminate disability discrimination on three fronts: employment (Title I, 42 U.S.C. §§ 12111-12117); public services offered by public agencies (Title II, 42 U.S.C. §§ 12131-12165); and public services and accommodations offered by private entities (Title III, 42 U.S.C. §§ 12161-12189).

<sup>102.</sup> Title II of the ADA forbids public entities, including the Defendants here, from discriminating against people with disabilities. 42 U.S.C. § 12132.

103. The ADA required adoption of implementing regulations. 42 U.S.C. § 12134 (attorney general to promulgate regulations). There are two regulations most relevant to the Olmstead decision and here; together they comprise the

“integration mandate” of the ADA.

104. The first regulation is the integration regulation, which states: “A public entity shall administer services, programs and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” 28 C.F.R. § 35.130(d). The second is the reasonable modifications regulation, which provides: “A public entity shall make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate conclusively that making the modifications would fundamentally alter the nature of the service, program, or activity.” 28 C.F.R. § 35.130(b)(7).
105. Unnecessary institutionalization is a form of discrimination prohibited by the ADA.
106. The assessment system established and administered by Defendants LEVINE and KLIEBERT , which utilizes the SIS assessment, and as administered by the agents of said Defendants, resulted in arbitrary and incorrect assessments and decisions regarding the support staffing needs of individuals served by the NOW Waiver. Such decisions risk causing the unnecessary institutionalization of participants in the NOW Waiver.
107. The assessment system established and administered by Defendants LEVINE and KLIEBERT , which utilizes the SIS assessment, and as administered by the agents of said Defendants, resulted in arbitrary and incorrect assessments and decisions regarding the support staffing needs of individuals served by the NOW Waiver. Such decisions risk causing the

unnecessary institutionalization of BRYAN STEIN, a participant in the NOW Waiver.

108. The Defendants' reduction in services violates the ADA's integration mandate because it forces or will likely force individuals not currently institutionalized, such as BRYAN STEIN, into institutional settings against their will.

#### **Fourth Cause of Action – Medicaid Act**

109. All the preceding allegations are hereby incorporated as if fully set forth herein.

110. The Medicaid Act provides federal funding to “enabl[e] each State, as far as practicable ... to furnish ... medical assistance on behalf of families with dependent children and of aged, blind, or disabled individuals, whose income and resources are insufficient to meet the costs of necessary medical services.” 42 U.S.C. § 1396-1). The Medicaid program is a jointly financed federal-state program that is administered by the States in accordance with federal guidelines.” Each state that elects to participate in the program must submit a plan to the federal government. 42 U.S.C. §§ 1396, 1396a. If the plan is approved, the state is entitled to Medicaid funds from the federal government for a percentage of the money spent by the state in providing covered medical care to eligible individuals. Id. § 1396b (a)(1).

111. The Act, among other things, outlines detailed requirements for [state] plan eligibility, 42 U.S.C. § 1396a, erects a complex scheme for allocating and receiving federal funds, id. § 1396b. Medicaid generally requires a State

to conform with federal guidelines prior to receiving federal funds; however, under 42 U.S.C. § 1315, CMS may waive compliance for projects and programs. 42 U.S.C. § 1315(a).

112. The NOW Waiver is established under the Medicaid Act as a “waiver” under 42 U.S.C. § 1315.

113. The assessment system established and administered by Defendants LEVINE and KLIEBERT , which utilizes the SIS assessment, and as administered by the agents of said Defendants, resulted in arbitrary and incorrect assessments and decisions regarding the support staffing needs of individuals served by the NOW Waiver. Such decisions violate the State Defendants obligations under the NOW Waiver in violation of the State’s approved Waiver plan.

114. The assignment of BRYAN STEIN to Level 1 is contrary to a proper assessment of his needs under the Medicaid Statute and the NOW Waiver.

115. The assessment system established and administered by Defendants LEVINE and KLIEBERT , which utilizes the SIS assessment, and as administered by the agents of said Defendants, resulted in arbitrary and incorrect assessments and decisions regarding the support staffing needs of individuals served by the NOW Waiver. Such decisions violate the State Defendants obligations under the NOW Waiver to BRYAN STEIN in violation of the State’s approved Waiver plan.

WHEREFORE, Plaintiff BRYAN STEIN demands judgment of Defendants including but not limited to a declaratory judgment and injunctive relief. Plaintiff also demands an award of attorney's fees, as well as all other relief to which he may be entitled.

Respectfully submitted,

s/ David Ferleger

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February 7, 2010