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STANLEY LIGAS, by his sister and next friend, Gina Foster; LORENE BIERMAN, by her guardians, Darlene and Joseph Bierman; DAVID CICARELLI, by his guardians James and Julianne Cicarelli; ISAIAH FAIR, by his guardian, Lutricia Fair; ADAM KULIG, by his guardian, Norb Kulig; JAMIE McELROY, by his guardian, Patricia McElroy; and JENNIFER WILSON, by her guardians, Nancy and Richard Wilson, on behalf of themselves and all others similarly situated, Plaintiffs, vs. BARRY S. MARAM, in his official capacity as Director of the Illinois Department of Healthcare and Family Services, and CAROL L. ADAMS, in her official capacity as Secretary of the Illinois Department of Human Services, Defendants.

No. 05 C 4331

UNITED STATES DISTRICT COURT FOR THE NORTHERN DISTRICT OF  
ILLINOIS, EASTERN DIVISION

*2005 U.S. Dist. Ct. Pleadings 54331; 2006 U.S. Dist. Ct. Pleadings LEXIS 18361*

April 26, 2006

Complaint

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**COUNSEL:** [\*1] attorneys for Plaintiffs, Barry G. Lowy (ARDC No. 6196719), Laura J. Miller (ARDC No. 6202721), Barry C. Taylor (ARDC No. 6199045), John W. Whitcomb (ARDC No. 6204744), EQUIP FOR EQUALITY, Chicago, Illinois, John I. Grossbart (ARDC No. 3126133), Kendra K. Hartman (ARDC No. 6257264), SONNENSCHN NATH & ROSENTHAL LLP, Chicago, Illinois, Max Lapertosa (ARDC No. 6276608), Kenneth M. Walden (ARDC No. 6273221), ACCESS LIVING OF METROPOLITAN CHICAGO, Chicago, Illinois, Benjamin S. Wolf (ARDC No. 3125607), AMERICAN CIVIL LIBERTIES UNION OF ILLINOIS, Chicago, Illinois, Judith A. Gran, PUBLIC INTEREST LAW CENTER OF PHILADELPHIA, Philadelphia, Pennsylvania.

**TITLE: FIRST AMENDED COMPLAINT FOR DECLARATORY AND INJUNCTIVE RELIEF**

**TEXT: CLASS ACTION**

### **INTRODUCTION**

1. Plaintiffs are individuals with mental retardation and other developmental disabilities who qualify for services under Defendants' system of long-term care for people with developmental disabilities, including Medicaid services.

They bring this action against state officials who administer Illinois' program for providing such services for people with developmental disabilities. Plaintiffs seek redress for Defendants' practice [\*2] of requiring them to reside in large, privately-run congregate care institutions - known as "intermediate care facilities for people with developmental disabilities" ("ICF-DDs") - as a condition of receiving the long-term care services they need and for which they qualify, in violation of Title II of the Americans with Disabilities Act, 42 U.S.C. § 12132 ("Title II"); Section 504 of the Rehabilitation Act, 29 U.S.C. § 794(a) ("Section 504"); Title XIX of the Social Security Act, 42 U.S.C. §§ 1396-1396v ("Title XIX") and 42 U.S.C. § 1983. Plaintiffs bring this action on their own behalf and on behalf of others similarly situated.

2. Like all human beings, Plaintiffs need "family relations, social contacts, work options, economic independence, educational advancement and cultural enrichment." *Olmstead v. L.C.*, 527 U.S. 581, 600 (1999). These needs can be met in community settings; Plaintiffs can appropriately be served in settings that would integrate them into the community while still meeting their need for services and support. Integration into the [\*3] community benefits people of all levels of developmental disabilities; indeed, those with the most severe disabilities have been shown to achieve the most progress in the community. Many people with developmental disabilities prefer to live in a home that is integrated in the community, rather than an institution. In addition, community-based programs are cost-effective alternatives to large institutions such as ICF-DDs.

3. Despite the demonstrated advantages of community-based programs, Defendants administer an antiquated system for serving people with developmental disabilities that relies heavily on large public and private institutions, including ICF-DDs. This system defies the national trend of serving people with developmental disabilities in the community. Illinois ranks 49th among states in its placement of people with developmental disabilities in small community settings. While paying lip-service to the value of community-based programs, Defendants have made paltry efforts to reduce the state's reliance on large institutions or to expand Illinois' community-based programs.

4. Further, Defendants do not have a comprehensive, effectively working plan for moving persons into [\*4] the community who are, or who are at risk of being, unnecessarily institutionalized. Defendants fail to advise ICF-DD residents and other individuals seeking developmental disability services that they may be eligible for community services and that they have the choice of such services; maintain no waiting list for community services; do not adequately evaluate residents of ICF-DDs or other individuals seeking services to determine if they could appropriately be served in a community setting; advise those people who seek community services that they can only obtain them in an "emergency" situation (which is not defined in any pertinent law or regulation); fail to provide community services to individuals who are capable of living in the community; and otherwise act arbitrarily in administering developmental disability services. Defendants channel Plaintiffs into ICF-DDs and severely curtail access to community services.

5. By requiring Plaintiffs to submit to institutionalization as a condition of receiving services, Defendants have caused Plaintiffs to experience unnecessary regression, deterioration, isolation and segregation. This segregation "perpetuates unwarranted assumptions" [\*5] that Plaintiffs "are incapable or unworthy of participating in community life." *Olmstead*, 527 U.S. at 600.

6. The "integration mandates" of Title II and Section 504 (implemented by 28 C.F.R. § 35.130(d) and 28 C.F.R. § 41.51(d)) require that state government services, programs and activities be provided in the most integrated setting appropriate to the needs of the person with a disability. The Supreme Court affirmed these mandates in *Olmstead*, finding that "unjustified institutional isolation of persons with disabilities is a form of discrimination." 527 U.S. at 600. Defendants have defied this mandate by clinging to a segregated, outmoded, and, for Plaintiffs, harmful institutional system and by failing to develop a comprehensive, effectively working plan to offer developmentally disabled individuals services in the most integrated setting appropriate to their needs.

7. In addition, Defendants' actions violate Title XIX's requirements that Defendants: (1) offer persons with developmental disabilities who are Medicaid-eligible a choice between institutional and community services, and inform them [\*6] of "feasible alternatives" under the Home and Community Based Services Waiver, which funds some

community services in Illinois, see 42 U.S.C. § 1396n(c)(2)(C); (2) ensure that community services are provided with "reasonable promptness," 42 U.S.C. § 1396a(a)(8); and (3) ensure that ICF-DDs are not unnecessarily utilized, through the use of effective assessments to determine whether persons could be served in community settings. See 42 U.S.C. §§ 1396a(a)(30)(A) & (B); 42 C.F.R. §§ 456.370-371.

8. Plaintiffs seek to enforce their legal rights to receive services in the community, and not in segregated, isolating institutions that deprive them of basic liberties.

### **JURISDICTION AND VENUE**

9. This is an action for declaratory and injunctive relief to enforce the rights of the Plaintiffs and the class they seek to represent under the Americans with Disabilities Act, 42 U.S.C. § 12132, Section 504 of the Rehabilitation Act, 29 U.S.C. § 794(a), Title XIX of the Social Security Act, 42 U.S.C. §§ 1396, 1396a [\*7] -1396v, and 42 U.S.C. § 1983.

10. Jurisdiction is proper pursuant to 28 U.S.C. § 1331 and 28 U.S.C. § 1343. Venue is proper in the Northern District of Illinois pursuant to 28 U.S.C. § 1391(b).

11. Declaratory relief is authorized by 28 U.S.C. § 2201 and Rule 57 of the Federal Rules of Civil Procedure. Injunctive relief is authorized by 28 U.S.C. § 2202 and Rule 65 of the Federal Rules of Civil Procedure.

### **THE PARTIES**

#### **Defendants**

12. Defendants are sued in their official capacities. They are: the Director of the Illinois Department of Healthcare and Family Services, Barry S. Maram, or his duly appointed successor, and the Secretary of the Illinois Department of Human Services, Carol L. Adams, or her duly appointed successor.

13. Barry S. Maram is the Director of the Illinois Department of Healthcare and Family Services ("IDHFS"), which is the designated Medicaid Single State Agency and is responsible for the oversight [\*8] and administration of the Medicaid program under Title XIX of the Social Security Act, including programs for persons with developmental disabilities. See 42 U.S.C. § 1396a(a)(5). In this capacity, Mr. Maram administers and funds the ICF-DD program as well as community-based residential services, including services provided under the Medicaid Home and Community-Based Services Waiver Program for Adults with Developmental Disabilities pursuant to 42 C.F.R. § 430.25(c)(2). Director Maram is responsible for ensuring these programs comply with federal law.

14. Carol L. Adams is the Secretary of the Illinois Department of Human Services ("DHS"), which, through its Division of Developmental Disabilities, is responsible for providing comprehensive services to people with developmental disabilities in Illinois, including both institutional and community residential services, to help them achieve self-sufficiency, independence and health to the maximum extent possible. She is also responsible for administering the State of Illinois' preadmission screening process, through which the State determines an individual's eligibility for institutional [\*9] or community services. DHS performs these screenings through local pre-admission screening ("PAS") agencies. There are 17 such agencies in the State, staffed by qualified mental retardation professionals. Secretary Adams is also responsible for ensuring compliance with state and federal laws that govern the provision of services to people with developmental disabilities, including the ADA and Section 504.

#### **The Named Plaintiffs**

##### **Stanley Ligas**

15. Stanley Ligas, age 37, has a diagnosis of Down Syndrome resulting in mild mental retardation, a developmental disability under 42 C.F.R. § 1009 and 405 ILCS § 5/1-106. He is eligible for Medicaid services.

16. Mr. Ligas is able to make decisions on his own behalf, with support from his siblings.

17. Mr. Ligas resided in his family's home until 1993, when both parents passed away. During the time he lived at home, he attended schools in Chicago. Mr. Ligas values frequent contact with his siblings and their families, remembering special dates and events in their lives.

18. After residing temporarily with family members, in 1994 Mr. Ligas moved to Sheltered Village, a 96-bed ICF-DD in Woodstock, Illinois.

19. Mr. Ligas [\*10] is independent in all of his activities of daily living. He is able to read and knows how to write checks and balance a checkbook. Mr. Ligas is a friendly and gregarious individual who has an engaging sense of humor. He expresses what he likes, dislikes, wants and needs.

20. While living at Sheltered Village, Mr. Ligas worked in a sheltered workshop environment, but later advanced to a combination of community job hours and the workshop. Having met the goals of the workshop, he "graduated" and worked briefly at a video store in Woodstock. When the store closed, Mr. Ligas' job ended. After being unemployed for several months, he was placed back in a sheltered workshop setting. Recently, the sheltered workshop was able to secure a part-time supported employment position for Mr. Ligas at Popeye's Chicken.

21. Mr. Ligas has expressed a strong desire to reside in a small community-based setting with one to three other individuals located in close proximity to one of his siblings. His Interdisciplinary Team at Sheltered Village identified his readiness to move to a community setting at his annual service plan meeting in 2004.

22. Sheltered Village informed his state-appointed PAS agency [\*11] that Mr. Ligas could handle and benefit from community placement. Despite this recommendation, Mr. Ligas remains at Sheltered Village.

23. With suitable supports and services, Mr. Ligas could live in the community. The community is the most integrated setting appropriate to Mr. Ligas' needs, but Defendants have only offered services in a segregated, institutional setting.

#### **Lorene Bierman**

24. Plaintiff Lorene Bierman, age 43, has a diagnosis of profound mental retardation. This is a developmental disability under *42 C.F.R. § 435.1009* and 405 ILCS § 5/1-106. She is eligible for Medicaid services.

25. Darlene and Joseph Bierman, Ms. Bierman's parents, are her legal co-guardians, and they are strong advocates on her behalf. Ms. Bierman visits her parents at their home on a regular basis.

26. Since 1991, Ms. Bierman has resided in Bethesda Lutheran Home in Aurora, Illinois, a 45-bed ICF-DD. Prior to moving to the Aurora ICF-DD, she resided at another large facility, Bethesda Lutheran Home in Watertown, Wisconsin, for nine years.

27. Ms. Bierman is non-verbal. She is able to communicate by using gestures and other sounds. She is easy-going, cooperative, [\*12] and gets along well with staff and peers. Ms. Bierman is able to indicate her personal preferences by favorably or unfavorably responding to staff initiations. Ms. Bierman attends church regularly and enjoys listening to the hymns.

28. While at Bethesda Lutheran Home, Ms. Bierman attends an adult day care program at Keeler Center in Aurora. She chooses her routine on a daily basis. An emphasis of this day program is to increase her pre-vocational skills and her ability to respond to verbal cues.

29. Ms. Bierman's parents would like her to move to a community-based residential program because they feel she will benefit from the smaller size residence and more attentive staff. They believe she will demonstrate greater adaptive

skills in a more home-like environment than at a large facility like Bethesda Lutheran Home.

30. Ms. Bierman was accepted into Bethesda's small community residential program in 2004 and her parents anticipated that she would have moved to there soon after. However, a DHS representative verbally informed Mrs. Bierman that her daughter would not be given funding for that program because she was not "an emergency."

31. With appropriate supports and services, Lorene [\*13] Bierman could live in a small group setting in the community. However, Defendants continue to only offer her services in a segregated, institutional setting.

#### **David Cicarelli**

32. David Cicarelli, age 32, is diagnosed with moderate mental retardation, a developmental disability under 42 C.F.R. § 435.1009 and 405 ILCS § 5/1-106. He is eligible for Medicaid services.

33. Mr. Cicarelli's parents, James and Julianne Cicarelli, are his legal co-guardians. Mr. Cicarelli lived with his parents in Arlington Heights, Illinois until 1997, when he moved to Riverside Foundation, a 96-bed ICF-DD facility located in Lincolnshire, Illinois.

34. Mr. Cicarelli continues to have a close relationship with his parents, whom he visits regularly. They have been his advocates and have attempted to secure the most independent and integrated setting for their son's needs.

35. Mr. Cicarelli is independent in most of his personal care skills. He is a friendly, engaging individual who enjoys dining out with friends, shopping, going to the movies, the library and to church. He also enjoys doing arts and crafts, painting and sewing.

36. After graduating from high school, [\*14] Mr. Cicarelli worked in a supermarket as part of a vocational training program. Since moving to Riverside Foundation, Mr. Cicarelli works at the Riverside Developmental Services day program. Mr. Cicarelli's 1995 Annual Review states that "he has reached his optimal level of functioning vocationally" in that setting. He is not working in the community, despite the ability to do so.

37. When Mr. Cicarelli was in his early twenties, his parents began seeking community-based residential alternatives to living at home. They felt strongly that he would benefit most from living in the community. However, there were no such services available. As a result, Mr. Cicarelli moved to Riverside Foundation, an ICF-DD which had immediate openings. Even after Mr. Cicarelli moved to this ICF-DD, his parents continued to pursue community services for him, as they did not feel that Riverside Foundation was an appropriate setting.

38. Most recently, approximately two years ago, Clearbrook, a service provider located near Mr. Cicarelli's family home, informed the Cicarelli's of opportunities for placement in one of its community homes. However, once Clearbrook learned that Mr. Cicarelli was placed at [\*15] the Riverside Foundation ICF-DD, it informed Mrs. Cicarelli that she would need to contact the PAS agency caseworker. The caseworker, in turn, told Mrs. Cicarelli that because her son was already being served, albeit in an institution, the state would not provide him with services in the community, and Mrs. Cicarelli was discouraged from even re-opening her son's case with them.

39. With appropriate supports and services, David Cicarelli would thrive in a small, more integrated community setting. Defendants, however, have only offered services in a segregated, institutional setting.

#### **Isaiah Fair**

40. Isaiah Fair, age 40, is diagnosed as having moderate mental retardation and epilepsy, which are developmental disabilities under 42 C.F.R § 435.1009 and 405 ILCS § 5/1-106.

41. Mr. Fair is eligible for Medicaid and has been receiving developmental disability services from Defendants. Until May 28, 2003, Mr. Fair was residing in Matteson Court, a 16-bed ICF-DD, in Matteson, Illinois.

42. Mr. Fair's mother and guardian, Lutricia Fair, was unhappy with his placement in the ICF-DD because it failed to provide adequate integration into the community, because the housing of 16 [\*16] individuals together with inadequate staff resulted in an atmosphere of turmoil, and because the staff of the ICF-DD failed to keep Ms. Fair informed about her son's medical problems. In May 2002, Ms. Fair requested that Mr. Fair's state-appointed PAS agent, Suburban Access, seek a placement for Mr. Fair in a small group home in the community to alleviate these problems. No such placement was offered.

43. In May 2003, Mr. Fair had a severe seizure at Matteson Court. Staff refused to call 911. Ms. Fair was present and called 911 from her cellular telephone. In response to this incident, Ms. Fair filed a complaint with the IDPH on her son's behalf. The IDPH determined that the ICF-DD committed medical neglect. Ms. Fair then removed her son from the facility and decided to keep him at home while she attempted to secure community residential services for him.

44. In June 2003, Ms. Fair again requested that Suburban Access find a community placement for her son. Suburban Access has assessed Mr. Fair and deemed him qualified for community services.

45. DHS, however, denied Mr. Fair's request for community placement on the grounds that he no longer was in an "emergency" situation. Instead, [\*17] DHS suggested a large ICF-DD or state-operated developmental center, which Ms. Fair has refused. Suburban Access, as state-assigned PAS agent for Mr. Fair, explained to Ms. Fair that the only way her son could have qualified for a community placement under existing DHS standards would be if she had left him in the life-threatening situation at Matteson Court, thereby creating an "emergency."

46. As a result, Mr. Fair continues to live at home without necessary supports and services to avoid the more restrictive environment of an ICF-DD. As an adult, it is appropriate for Mr. Fair to live in the community with peers, rather than in his mother's home. Additionally, because Ms. Fair must care for her son, she is unable to work and supports her son with her limited savings. Mr. Fair will not be able to continue to live with his mother and will need out-of-home care, and so is at risk of institutionalization.

47. Suburban Access has not found an appropriate day program for Mr. Fair and has been unwilling to provide transportation for this purpose. Ms. Fair finally found a day program for her son with the assistance of a social worker at Ingalls Hospital. Mr. Fair has been attending the [\*18] Addus Day Program in Homewood since July of 2004. Mr. Fair has been waiting approximately three years for residential community services.

48. With appropriate supports and services, Mr. Fair could live in the community. The community is the most integrated setting appropriate to Mr. Fair's needs, but Defendants have only offered services in a segregated, institutional setting.

### **Adam Kulig**

49. Adam Kulig, age 22, resides in Johnston City with his father and guardian, Norb Kulig. Adam is diagnosed with moderate mental retardation, a developmental disability under *42 C.F.R. § 435.1009* and 405 ILCS § 5/1-106. He is eligible for Medicaid services. In May of 2005, Adam graduated from Marion High School and entered into a day training program.

50. Due to Adam's cognitive disabilities, he cannot be left unsupervised. His father is a single parent who is employed full-time and paid on an hourly basis as a maintenance worker. Adam attends a day program, but the hours of the program are shorter than the hours of his father's work day. Adam's father must arrive at work late and leave work early to be with Adam before and after the day program. This reduces [\*19] his wages and jeopardizes his job. Norb Kulig faces the impossible choice of leaving Adam alone or quitting his job to care for Adam.

51. Adam wants to move to a small residential community program close to home so that he can live with people his own age, but at the same time be close to his family and access the community where he has grown up. He is very social and likes being with people.

52. In August 2004, Norb Kulig contacted Adam's state-assigned PAS agent, Southern Illinois Case Coordination Services, and submitted a request for Adam to live in a small group home near the family home. The PAS agent deemed Adam appropriate for such a placement, and a provider agreed to serve him. On September 28, 2004, Southern Illinois Case Coordination Services submitted a funding request for Adam's residential placement to DHS.

53. On October 22, 2004, DHS denied Adam Kulig's request for community residential placement because DHS did not consider Adam's situation an "emergency." Adam's father was shown an ICF-DD, but feels such a placement would be inappropriate for Adam due to its size.

54. DHS continues to fail and refuse to provide Adam Kulig with an appropriate placement in a small [\*20] community group home.

55. With appropriate supports and services, Adam Kulig could live in the community. The community is the most integrated setting appropriate to Adam Kulig's needs, but Defendants have only offered services in a segregated, institutional setting.

#### **Jamie McElroy**

56. Jamie McElroy, age 22, is diagnosed with moderate mental retardation, a developmental disability under 42 C.F.R. § 435.1009 and 405 ILCS § 5/1-106. Mr. McElroy graduated from public high school.

57. Mr. McElroy currently lives at home with his mother in Williamsville, Illinois. He has been accepted to, and wishes to live in, a community placement in the Springfield, Illinois, area near his family.

58. Mr. McElroy's state-assigned PAS agent found him eligible for Medicaid developmental disability services and community placement.

59. Nevertheless, DHS denied Mr. McElroy's request for community placement, stating that: "Currently funded options must be pursued prior to consideration of new funding." The only "currently funded options" are institutions.

60. With appropriate supports and services, Mr. McElroy could live in the community. The community is the most [\*21] integrated setting appropriate to Mr. McElroy's needs, but Defendants have only offered services in a segregated, institutional setting.

#### **Jennifer Wilson**

61. Jennifer Wilson, age 20, has moderate mental retardation, cerebral palsy and epilepsy, which are developmental disabilities under 42 C.F.R. § 435.1009 and 405 ILCS § 5/1-106. Her disabilities are the result of a brain hemorrhage that she incurred when she was a day old. She uses a wheelchair for mobility. She graduated from Springfield High School.

62. Ms. Wilson currently lives at home with her parents in Springfield, Illinois, but receives no services. She wishes to live in a community placement, and has been accepted into such a program by United Cerebral Palsy of Land of Lincoln.

63. Ms. Wilson's state-assigned PAS agent found her eligible for Medicaid developmental disability services and community placement.

64. DHS denied Ms. Wilson's request for community placement, stating only that Ms. Wilson did "not meet the target population criteria."

65. With appropriate supports and services, Ms. Wilson could live in the community. The community is the most integrated setting appropriate [\*22] to Ms. Wilson's needs, but Defendants have only offered services in a segregated,

institutional setting.

### **CLASS ACTION ALLEGATIONS**

66. The named Plaintiffs bring this action as a class action pursuant to Rule 23, sections (a) and (b)(2), of the Federal Rules of Civil Procedure.

67. The class of individuals that the named Plaintiffs seek to represent consists of those persons in Illinois who:

(1) have mental retardation and/or other developmental disabilities and who qualify for long-term care services;

(2) with appropriate supports and services, could live in the community and who would not oppose community placement; and

(3) either are institutionalized in private ICF-DDs with nine or more residents or are living in a home-based setting and are at risk of institutionalization because of their need for services.

68. The class is so numerous that joinder of all Plaintiffs is impracticable. The exact number of individuals in the class is not known to the Plaintiffs, but is believed to number in the thousands.

69. The claims of the named plaintiffs are common to those of the class and raise common issues of fact and law, including, among others: whether [\*23] Defendants are providing services to developmentally disabled individuals in the most integrated setting appropriate to their needs; whether Defendants have a comprehensive, effectively working plan for achieving that goal; whether Defendants administer a waiting list for community services that moves at a reasonable pace; whether Defendants adequately determine whether class members are eligible for community services; whether Defendants adequately inform developmentally disabled individuals of their right to community services; and whether Defendants violate Title XIX of the Social Security Act, the Americans with Disabilities Act and Section 504 of the Rehabilitation Act by failing to provide community-based services to qualified individuals.

70. Plaintiffs' claims that Defendants have failed to administer the state's developmental disabilities program so as to provide services in the most integrated setting appropriate to their needs are typical of the claims of the class.

71. Plaintiffs will fairly and adequately protect the interests of the class because they suffer from deprivations identical to those of the class members and have been denied the same federal rights that they [\*24] seek to enforce on behalf of the other class members, many of whom are unable to pursue claims on their own behalf as a result of their disabilities, their limited financial resources, and/or the actions of the Defendants to deprive them of their rights. Plaintiffs' interests in obtaining injunctive relief for the violations of their legal rights and privileges are consistent with and not antagonistic to those of any person within the class. Furthermore, Plaintiffs' counsel has extensive experience in the areas of class action litigation and civil rights laws concerning people with disabilities.

72. Defendants have acted or refused to act on grounds generally applicable to all members of the class by unnecessarily segregating class members. Defendants have failed to inform class members of their right to community services; failed to perform appropriate assessments of class members' community service needs; failed to provide them with services in the most integrated setting appropriate to their needs, and failed to provide services with reasonable promptness. Therefore, declaratory and injunctive relief with respect to the entire class is appropriate.

### **STATEMENT OF THE CASE** [\*25]

#### **The Integration Mandates of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act**

73. In 1990, Congress enacted the Americans with Disabilities Act, *42 U.S.C. §§ 12101 - 12181*, to advance the



civil rights of people with disabilities.

74. The ADA's purpose and goal is "the elimination of discrimination against individuals with disabilities." 42 U.S.C. § 12101(b)(1).

75. In enacting the ADA, Congress stated that "historically, society has tended to isolate and segregate individuals with disabilities" and that such forms of discrimination "continue to be a serious and pervasive social problem." 42 U.S.C. § 12101(a)(2).

76. Congress further determined that "the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic sufficiency for such individuals." 42 U.S.C. § 12101(a)(8).

77. Title II of the ADA provides that "no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or [\*26] be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity." 42 U.S.C. § 12132 (emphasis added).

78. Discrimination under Title II of the ADA includes unnecessary segregation and institutionalization. As the Supreme Court stated in *Olmstead v. L.C.*, 527 U.S. 581 (1999), "unjustified institutional isolation of persons with disabilities is a form of discrimination" because "[i]n order to receive needed medical services, persons with mental disabilities must, because of those disabilities, relinquish participation in community life ..." *Id.* at 600-01.

79. The regulations to the ADA codify the prohibition against unnecessary segregation and institutionalization. 28 C.F.R. § 35.130(d) ("A public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities"). Section 504 has an identical mandate. 28 C.F.R. § 41.51(d) ("Recipients shall administer programs and activities in the most integrated setting [\*27] appropriate to the needs of qualified handicapped persons").

80. Furthermore, the ADA prohibits public entities from utilizing "criteria or methods of administration" that have the effect of subjecting qualified individuals with disabilities to discrimination, which includes unnecessary institutionalization. 28 C.F.R. § 35.130(b)(3). Section 504 has an identical mandate. 45 C.F.R. § 84.4(b)(4); 28 C.F.R. § 41.51(b)(3).

## **The Illinois Medicaid Program for Persons with Developmental Disabilities**

### **A. Illinois' Participation in Medicaid**

81. Medicaid is a joint federal-state program through which the federal government reimburses a portion of expenses incurred by states to furnish health care services to low-income people, including services to persons with developmental disabilities.

82. States are not required to participate in the Medicaid program, but if they do, they must comply with the requirements of Title XIX of the Social Security Act, 42 U.S.C. §§ 1396 - 1396v. Every state that elects to participate must submit a plan to the United States [\*28] Department of Health and Human Services (HHS). This plan must contain reasonable standards to achieve the objectives and requirements of Title XIX. *Id.* § 1396a(a)(17).

83. One of Title XIX's primary objectives is "to help families and individuals attain or retain capacity of independence and self care ..." 42 U.S.C. § 1396.

84. Certain services under Title XIX are "mandatory" and must be provided to all eligible individuals. 42 U.S.C. § 1396a(a)(10)(A) (incorporating 42 U.S.C. §§ 1396d(a)(1-5), (17), (21)). States may additionally provide "optional" services, including ICF-DD (referred to as ICF/MR in Title XIX). *Id.* § 1396d(a)(15). However, once a state elects to

provide an optional service that service becomes part of the state's Medicaid plan and is subject to all requirements of Title XIX. Id. § 1396a(a)(1).

85. Illinois participates in Medicaid and its plan, approved by HHS, includes ICF-DD services.

#### **B. Medicaid Home and Community Based Services Waivers**

86. Title XIX also allows states to "waive" certain Medicaid requirements in order to enable people with disabilities to receive [\*29] services in the community as opposed to institutions. *42 U.S.C. § 1396n(c)*; *42 C.F.R. § 441.300*. These are known as "Medicaid Home and Community Based Services waivers" ("HCBS waiver"). States can receive Medicaid reimbursement for waiver services up to the average cost of institutional care, including the cost of care in an ICF-DD. *42 U.S.C. § 1396n(c)(2)(D)*.

87. Illinois has an HCBS waiver for people with developmental disabilities. This waiver allows people who would otherwise be institutionalized to receive services in community settings, including their own home, their family home, or a community or other residential arrangement providing necessary care and services. These settings offer far more freedom and community integration than do ICF-DDs.

88. Although states must apply for a specific number of slots for their HCBS waiver programs, there is no limit on how many slots a state may apply for. Historically, the federal government has liberally granted state requests for additional waiver slots. The federal government has informed states that the lack of available waiver slots does not absolve a state [\*30] from complying with the ADA's integration mandate. See Letter from U.S. Dep't of Health and Human Servs. to State Medicaid Directors at 4-5 (Jan. 10, 2001). Since the Olmstead decision, the federal government has encouraged and provided financial incentives to states to transfer people from institutions to the community.

#### **C. Title XIX's Requirements**

89. Title XIX requires that individuals eligible for Medicaid be given the opportunity to choose alternatives to institutional care, if available under the Medicaid plan, and that such individuals be afforded their choice of placement options and services. *42 U.S.C. § 1396n(c)(2)(C)*.

90. Title XIX additionally requires states to "provide that all individuals wishing to make an application for medical assistance under the plan shall have the opportunity to do so, and that such assistance shall be furnished with reasonable promptness to all eligible individuals." *42 U.S.C. § 1396a(a)(8)* (emphasis added).

91. Finally, under Title XIX, states must ensure against "unnecessary utilization" of ICF-DD services, *42 U.S.C. § 1396a(a)(30)(A)*, and must ensure [\*31] residents are screened and assessed prior to admission to determine whether their needs can be met in the community. *42 U.S.C. § 1396a(a)(30)(B)*; *42 C.F.R. §§ 456.370-71*.

#### **D. Defendants' Unnecessary Segregation of People with Developmental Disabilities in ICF-DDs**

92. In Illinois, approximately 6,250 people live in 246 private ICF-DDs with nine or more people, with some facilities housing hundreds of people. As state officials have acknowledged, these ICF-DDs are institutions and do not qualify as community settings.

93. An ICF-DD is not like a home but is rather a large and often self-contained facility, where recreational activities, social activities and medical care are provided in the same building or on the same campus where residents sleep and eat.

94. Because they are large, segregated and isolated from the rest of society, ICF-DDs inhibit meaningful community involvement by depriving residents of the opportunity to interact with non-disabled people in non-custodial relationships in the community. Residents are denied the experiences of observing how other people behave or interact,

learning and developing age-appropriate behavior, and experiencing [\*32] the dignity and freedom of living in the community as normally as possible.

95. ICF-DD residents often live in large rooms with other residents and use communal bathrooms. Living areas lack privacy, are cold and unwelcoming, are sparsely furnished and do not contain furnishings or personal items one would normally associate with a home. Residents have few places to store their personal belongings.

96. The congregate nature of ICF-DDs prevents residents from expressing their individuality or freedom of association. Residents are deprived of the freedom to choose or reject their meals, their clothes, their roommates and their activities. They do not assist in shopping for food or personal items or in preparation of meals. They do not determine when and how they interact with their friends and family. As a result, many residents have regressed and become less independent.

97. Many ICF-DD residents are capable of living in the community with appropriate supports and services. For these individuals, segregation and institutionalization in ICF-DDs is unnecessary. Rather, the community is the most integrated setting appropriate to their needs.

98. Like Plaintiffs Fair, Kulig, McElroy [\*33] and Wilson, many persons with developmental disabilities who are eligible for Medicaid services live at home with parents or other family members, even at the cost of doing without needed services, because Defendants have not provided sufficient community alternatives. These Plaintiffs are in imminent danger of institutionalization because Defendants have denied them the community services they need to avoid institutionalization.

99. Defendants do not provide information about community services to many people with developmental disabilities, including members of the Plaintiff class.

100. Defendants do not provide Plaintiffs or class members the choice between institutional and community services.

101. Defendants do not systematically evaluate persons already residing in ICF-DDs to ascertain if they could be served in the community.

102. Defendants deny community residential services to persons already evaluated by the Defendants through the pre-screening system and determined capable of living in the community.

103. Defendants do not maintain a waiting list for community residential services. Defendants allocate community residential services in an arbitrary and capricious fashion, [\*34] often ignoring the recommendations of the PAS agencies, the requirements of the State's own Medicaid Plan, and federal law.

104. By arbitrarily denying community placement, Defendants have caused substantial, irreparable harm and prejudice to Plaintiffs as well as all similarly situated individuals with developmental disabilities, including unnecessary institutionalization or risk thereof, loss of life skills, loss of opportunities to develop to their fullest potential, and aggravation of their physical, mental, and emotional conditions.

## **LEGAL CLAIMS**

### **COUNT I: THE AMERICANS WITH DISABILITIES ACT**

105. Plaintiffs reallege paragraphs 1 through 104 as though fully set forth herein.

106. Plaintiffs and the members of the class are qualified individuals with disabilities within the meaning of the ADA, 42 U.S.C. § 12131(2).

107. Title II of the ADA requires that "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)

108. Regulations implementing Title II of the ADA provide that "a [\*35] public entity may not, directly or through contractual or other arrangements, utilize criteria or other methods of administration: (i) that have the effect of subjecting qualified individuals with disabilities to discrimination on the basis of disability; [or] (ii) that have the purpose or effect of defeating or substantially impairing accomplishment of the objectives of the entity's program with respect to individuals with disabilities ..." 28 C.F.R. § 35.130(b)(3).

109. Plaintiffs and class members qualify for community services, and the community is the most integrated setting appropriate to meet their needs. Nevertheless, Defendants have denied them access to community placement and required that they be confined in segregated facilities in order to receive placement and services.

110. Plaintiffs and the members of the class are institutionalized in ICF-DDs with nine or more residents, or are living in a home-based setting and are at risk of institutionalization because of their need for community residential services. By requiring that Plaintiffs and class members be confined in the segregated institutional setting of ICF-DDs as a condition of receiving [\*36] services, rather than providing services in integrated community settings, Defendants violate the ADA's integration mandate.

111. Further, Defendants' criteria and methods of administering Illinois' long-term care system for people with developmental disabilities subject Plaintiffs to illegal discrimination because they unnecessarily segregate Plaintiffs in ICF-DDs.

112. It would not fundamentally alter the programs, services, or activities of the Defendants to provide Plaintiffs and class members with services in the community.

113. Defendants do not have a comprehensive, effectively working plan for serving people with developmental disabilities in the most integrated setting appropriate for their needs.

## **COUNT II: SECTION 504 OF THE REHABILITATION ACT**

114. Plaintiffs reallege paragraphs 1 through 113 as though fully set forth herein.

115. Plaintiffs are qualified individuals with disabilities under Section 504 of the Rehabilitation Act, 29 U.S.C. § 794(a).

116. Defendants direct state agencies that receive federal financial assistance.

117. The regulations to Section 504 provide that: "Recipients shall administer programs and activities in [\*37] the most integrated setting appropriate to the needs of qualified handicapped persons." 28 C.F.R. § 41.51(d).

118. The Section 504 regulations further prohibit recipients of federal financial assistance from "utiliz[ing] criteria or methods of administration ... (i) [t]hat have the effect of subjecting handicapped persons to discrimination on the basis of handicap; [or] (ii) that have the purpose or effect of defeating or substantially impairing accomplishment of the objectives of the recipient's program with respect to handicapped persons." 28 C.F.R. § 41.51(b)(3); 45 C.F.R. § 84.4(b).

119. Plaintiffs and class members qualify for community services, and the community is the most integrated setting appropriate to meet their needs. Nevertheless, Defendants have denied them access to community services and have only offered them services in segregated institutional facilities.

120. By requiring that Plaintiffs and class members be confined unnecessarily in segregated environments as a condition of receiving services, rather than providing services in integrated community settings, Defendants violate

Section [\*38] 504's integration mandate.

121. Further, Defendants' criteria and methods of administering Illinois' system of long-term care for people with developmental disabilities subject Plaintiffs to illegal discrimination because they unnecessarily segregate Plaintiffs in ICF-DDs.

122. It would not fundamentally alter Defendants' programs, services, or activities to provide Plaintiffs and class members with services in the community.

### **COUNT III: TITLE XIX OF THE SOCIAL SECURITY ACT**

123. Plaintiffs reallege paragraphs 1 through 122 as though fully set forth herein.

124. Illinois participates in the Medicaid program and has chosen to provide both ICF-DD services and HCBS waivers for eligible persons under its Medicaid plan.

125. Plaintiffs are recipients of, or are eligible for, Medicaid.

#### **A. Failure to Provide Choice between ICF-DD and HCBS Waiver Services**

126. Plaintiffs require the level of care provided in an ICF-DD. Title XIX requires that when Plaintiffs are determined to be likely to require the level of care provided in an ICF-DD, states must inform them of feasible alternatives under the HCBS waiver and give them a choice of either ICF-DD or waiver services. *42 U.S.C. § 1396n(c)(2)(C)* [\*39] , 42 C.F.R. § 441.302(d).

127. Despite this requirement, Defendants have not given Plaintiffs the choice of community services available under the HCBS waiver for people with developmental disabilities.

#### **B. Failure to Provide Services with Reasonable Promptness**

128. Title XIX requires states to provide Medicaid benefits to all eligible persons with reasonable promptness. *42 U.S.C. § 1396a(a)(8)*. Provision of services must not be delayed by the agencies' administrative procedures. 42 C.F.R. § 435.930(a).

129. Plaintiffs qualify for both ICF-DD services and HCBS waiver services. Defendants have failed to provide HCBS waiver services with reasonable promptness.

#### **C. Unnecessary Utilization of ICF-DD Services**

130. Title XIX requires participating states to implement any "methods and procedures ... as may be necessary to safeguard against unnecessary utilization" of institutional care, including ICF-DDs. *42 U.S.C. § 1396a(a)(30)(A)*. In accordance with this requirement, states must ensure that "each admission to a[n] ... intermediate care facility for the mentally retarded ... is reviewed or screened in accordance with criteria [\*40] established by medical and other professional personnel...." *Id.* § 1396a(a)(30)(B).

131. Regulations implementing this requirement provide that, prior to admission to an ICF-DD, "an interdisciplinary team of health professionals must make a comprehensive medical and social evaluation and, where appropriate, a psychological evaluation of each applicant's or recipient's need for care in the ICF." *42 C.F.R. § 456.370(a)*.

132. The regulations further require that if an ICF resident's "needs could be met by alternative services that are currently unavailable, the facility must enter this fact in the recipient's record and begin to look for alternative services." *42 C.F.R. § 456.371*.

133. Defendants' methods and procedures cause unnecessary utilization of ICF-DD services for people with developmental disabilities. Defendants fail to ensure that people with developmental disabilities are adequately evaluated to determine their need for institutional care. Additionally, Defendants fail to ensure provision of community services for persons found not to require institutional care. As such, Defendants violate these requirements of [\*41] Title XIX.

#### **PRAYER FOR RELIEF**

WHEREFORE, the Plaintiffs individually and on behalf of the class, respectfully request that the Court:

A. Enter an order certifying the named Plaintiffs as representatives for a class consisting of those persons in Illinois who:

- (1) have mental retardation and/or other developmental disabilities and who qualify for long-term care services;
- (2) with appropriate supports and services, could live in the community and who would not oppose community placement; and
- (3) either are institutionalized in private ICF-DDs with nine or more residents or are living in a home-based setting and are at risk of institutionalization because of their need for services.

B. Declare that Defendants' failure to provide Plaintiffs with services in the most integrated setting appropriate to their needs violates Title II of the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, and Title XIX of the Social Security Act.

C. Issue a permanent injunction:

- (1) requiring Defendants to inform developmentally disabled individuals in the State that they may be eligible for community services and that they have the choice of [\*42] such services;
- (2) requiring Defendants promptly to determine Plaintiffs' and class members' eligibility for community services;
- (3) prohibiting Defendants from arbitrarily denying eligibility to individuals who are capable of living in a community setting with appropriate supports and services; and
- (4) requiring Defendants promptly to provide eligible Plaintiffs and class members with appropriate services sufficient to allow them to live in the most integrated setting appropriate to their needs.

D. Grant such other and further relief as this Court deems just and proper, including an award of reasonable attorneys' fees, litigation expenses and costs.

Respectfully submitted:

Dated: April 26, 2006

By: /s/ Kendra K. Hartman  
One of the attorneys for Plaintiffs

Barry G. Lowy (ARDC No. 6196719)

Laura J. Miller (ARDC No. 6202721)  
Barry C. Taylor (ARDC No. 6199045)  
John W. Whitcomb (ARDC No. 6204744)  
EQUIP FOR EQUALITY  
20 North Michigan Avenue, Suite 300  
Chicago, Illinois 60602  
Tel: (312) 341-0022  
Fax: (312) 341-0295

John I. Grossbart (ARDC No. 3126133)  
Kendra K. Hartman (ARDC No. 6257264)  
SONNENSCHN NATH & ROSENTHAL LLP  
7800 Sears [\*43] Tower  
Chicago, Illinois 60606  
Tel: (312) 876-8000  
Fax: (312) 876-7934

Max Lapertosa (ARDC No. 6276608)  
Kenneth M. Walden (ARDC No. 6273221)  
ACCESS LIVING OF METROPOLITAN CHICAGO  
614 West Roosevelt Road  
Chicago, Illinois 60607  
Tel: (312) 253-7000  
Fax: (312) 253-7001

Benjamin S. Wolf (ARDC No. 3125607)  
AMERICAN CIVIL LIBERTIES UNION OF ILLINOIS  
180 North Michigan Avenue, Suite 2300  
Chicago, Illinois 60601  
Tel: (312) 201-9740  
Fax: (312) 201-9760

Judith A. Gran  
PUBLIC INTEREST LAW CENTER OF PHILADELPHIA  
125 S. Ninth Street, Suite 700  
Philadelphia, Pennsylvania 19107  
Tel: (215) 627-7100  
Fax: (215) 627-3183