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ARTICLE

Dead to Rights: A Father's Struggle to Secure Mental Health Services For His Son

April Land*

*"This case is about people—children and adults who are sick, poor and vulnerable—for whom life, in the memorable words of poet Langston Hughes, 'ain't been no crystal stair.' It is written in the dry and bloodless language of 'the law' But let there be no forgetting the real people to whom this dry and bloodless language gives voice: anxious, working parents who are too poor to obtain medications or heart catheter procedures or lead poisoning screens for their children, AIDS patients unable to get treatment, elderly persons suffering from chronic conditions like diabetes and heart disease who require constant monitoring and medical attention. Behind every 'fact' found herein is a human face and the reality of being poor in the richest nation on earth."*¹

INTRODUCTION

Federal law provides strong statutory rights and protections for children with mental disabilities and mental illnesses. These rights include Medicaid entitlement to all medically necessary services,² and special education rights to "free and appropriate public education."³ Unfortunately, there is a vast and sometimes fatal gap between children's legal rights and the actual services that they can access in their communities. The Office of the United States Surgeon General has declared that:

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1. *Salazar v. District of Columbia*, 954 F. Supp. 278, 281 (D.D.C. 1996) (citing Langston Hughes, "Mother to Son").

2. See 42 U.S.C.A. § 1396 (West Supp. 2000).

3. 20 U.S.C.A. § 1400(d)(1)(A) (West 2000).

[t]he burden of suffering experienced by children with mental health needs and their families has created a health crisis in this country. Growing numbers of children are suffering needlessly because their emotional, behavioral, and developmental needs are not being met by those very institutions which were explicitly created to take care of them. It is time that we as a Nation took seriously the task of preventing mental health problems and treating mental illness in youth.⁴

Parents across the nation, increasingly desperate to alleviate their children's suffering, are going so far as to give up custody in the hope of securing mental healthcare for them. This growing phenomenon is reflected in the front page headlines of the New York Times,⁵ and thirteen states have passed laws to prohibit exchanging custody for care.⁶ While six and a half million children with disabilities have been identified and are receiving special education services,⁷ it is unclear how many of them are, in fact, receiving the range of services that they need. As welfare reform, managed care and a shrinking public healthcare system limit access to services, many poor and minority youth with psychiatric disorders may "increasingly fall though the cracks into the juvenile justice system,"⁸ which is poorly equipped to help them.⁹

This Article analyzes the gap between children's statutory rights and their actual access to services within the educational, medical and juvenile justice systems by focusing on the experience of a father who sought services for his son suffering from mental illness and a mental disability. For almost twenty years, the father, Mr. Patrick Martinez,¹⁰ sought services for his child through the public education system, Medicaid, and the juvenile justice system. Mr. Martinez

4. U.S. Public Health Service, *Report of the Surgeon General's Conference on Children's Mental Health: A National Action Agenda*, 3 (Washington, D.C., Department of Health and Human Services, 2000), at <http://www.surgeongeneral.gov/topics/cmh/childreport.htm>.

5. Shailla K. Dewan, *Parents of Mentally Ill Children Trade Custody for Care*, N.Y. TIMES, Feb. 16, 2003, at A35.

6. *Id.*

7. AM. YOUTH POLICY FORUM AND CTR. ON EDUC. POLICY, *Twenty Five Years of Educating Children with Disabilities: The Good News and the Work Ahead* 4 (2001), available at <http://www.aypf.org>.

8. Linda A. Teplin et. al, *Psychiatric Disorders Common Among Detained Youth*, National Institutes of Health, National Institute of Mental Health (Dec. 2002 Archives of General Psychiatry).

9. *Id.*

10. Mr. Martinez and his family have expressed a strong desire to have Jesse's story told, using his real name. The author also spoke with Jesse several times during his lifetime, and Jesse said that he wanted his story told. Mr. Martinez has explained that when he began his effort to secure services for his family almost twenty years ago, he refused any press or publicity about his family's plight. After decades of struggling to secure services without success and without legal redress for the wrongs suffered by his children, he feels strongly that Jesse's story should be told. The author served as next friend to Jesse in the class action lawsuit described in Section III of this Article. The facts of Jesse's story were gathered during the course of that relationship, beginning in January 1999, and during a series of formal interviews with Mr. Patrick Martinez on July 19, 2003, July 22, 2002 and August 9, 2002. Where no independent sources are cited for facts of Jesse's life, the facts were verified by Mr. Martinez. (Verification is on file with the Georgetown Journal on Poverty Law & Policy).

attended school meetings, filed administrative complaints, appeared regularly in juvenile delinquency proceedings involving his son, and eventually became involved in a class action lawsuit against New Mexico. Despite these persistent efforts, Mr. Martinez was unable to secure appropriate services for his son, Jesse. In the fall of 2001, Jesse was murdered on the streets of Albuquerque at the age of twenty.

This Article lays out the strong statutory rights and protections in the areas of special education and contrasts them with Mr. Martinez's actual experience in trying to secure appropriate education for Jesse. Medicaid is then addressed in a similar manner,¹¹ describing the strong legal protections and revealing how Jesse was denied necessary treatment and services. The Article then tracks father and son as they experienced the juvenile justice system: from probation to juvenile detention to adult jail.

The Article concludes that the agencies responsible for administering federal law must not be permitted to continue to avoid compliance with clear statutory mandates. They are failing to meet their legal responsibilities by asserting that services should be provided by other agencies, rather than coordinating efforts with those other agencies to ensure that children get services that are necessary and required by federal law.

This Article attempts to identify who, where, how, and why social service systems fail children despite the clear protections for them under federal law. It describes the harsh reality of being a poor, disabled child in the richest nation on earth.

I. JESSE MARTINEZ

In the wee hours of September 12, 2001, Jesse Martinez was visiting friends—a family that lived near his home in the San Jose neighborhood of Albuquerque. The family loved Jesse. He had protected their great-grandson when the two were in the detention center together. The home was well-known to Jesse. It was the house where he had started using drugs, and where he hung out. That night, as he often would, Jesse went out onto the street to check out the action. Accounts of what happened next differ. Some say it was a dispute over territory. Some say it was a drug deal gone bad. But out on the street, Jesse was shot in the back. Jesse then returned inside the house, bleeding and looking for help. The family, fearing the police, turned him back onto the street, where Jesse was shot again—in the face and in the abdomen. He was shot a total of seven times. Jesse died before medical assistance arrived.

In the twenty years preceding that night, Jesse's father worked, pleaded, and struggled with the systems that were set up to help children like Jesse. Jesse suffered from schizophrenia. He had mental retardation. He lived in a neighbor-

11. 42 U.S.C.A. § 1396 (West Supp. 2000).

hood plagued by poverty, drugs, gangs and violence. While Jesse was identified as having behavioral problems in as early as kindergarten, he never received the treatment or services necessary to survive in his neighborhood. Individual teachers, nurses, doctors and social workers made sincere efforts to help Jesse, but for over twenty years, the education system, Medicaid, and the juvenile justice system failed.

II. SPECIAL EDUCATION IS FEDERALLY REQUIRED TO HELP CHILDREN BENEFIT FROM EDUCATION

Federal special education law is designed to ensure that all children with disabilities have a meaningful opportunity to learn.¹² Federal statutory requirements are comprehensive and clear. All children with disabilities, regardless of the severity of their disabilities, are entitled to appropriate education.¹³ Yet the gap between the statutory requirements and the actual provision of services results in a vital missed opportunity to provide children with the opportunity to learn the skills that they need to survive and thrive.

The federal Individuals with Disabilities Education Act (IDEA) was enacted to protect the rights of children with disabilities as well as the rights of their parents.¹⁴ The Congressional Findings in support of IDEA state that:

[d]isability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society. Improving educational results for children with disabilities is an essential element of our national policy of ensuring equality of opportunity, full participation, independent living and economic self-sufficiency for individuals with disabilities.¹⁵

To meet these important national policy objectives, IDEA requires states to ensure that all children with disabilities have access to a "free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for employment and independent living."¹⁶ The rights under IDEA were intended to address not only the academic needs of children with learning disabilities, but also to comprehensively address the behavioral needs of children in the public school system, and to prepare them for transition to adult life.

Disabled children are further protected from discrimination in education under § 504 of the Rehabilitation Act of 1973, which prohibits recipients of federal

12. U.S.C.A. § 1400(d)(1)(A) (West 2000).

13. *Timothy W. v. Rochester N.H. Sch. Dist.*, 875 F.2d 954, 972-73 (1st Cir.1989), *cert denied* 493 U.S. 983 (1989).

14. *See* 20 U.S.C.A. § 1400(d) (West 2000).

15. 20 U.S.C.A. § 1400 (c)(1) (West 2000).

16. 20 U.S.C.A. § 1400 (d)(1)(A) (West 2000); 34 C.F.R. § 300.1(a) (West 2003).

funds from discriminating against disabled individuals. Commonly referred to as § 504, the Act is a civil rights act and has an even broader definition of disability than IDEA.¹⁷ Section 504 compels public school systems to provide free appropriate public education in the least restrictive environment, regardless of the nature or severity of a student's disability.¹⁸ Thus, § 504 provides additional statutory protections for children with disabilities, creating a separate cause of action to seek compliance with some of the following provisions of IDEA regarding the right to free and appropriate public education and placement in the least restrictive environment.¹⁹

A. *A Right to Free and Appropriate Education Under IDEA*

IDEA requires the State²⁰ to "conduct a full and individual initial evaluation"²¹ to determine whether a child has a disability and what educational needs are present.²² This initial evaluation must be used to develop an Individualized Education Program (IEP) for the child. The IEP is crucial to the delivery of special education; it is the "centerpiece of the statute's education delivery system for disabled children."²³ It details the education and related supportive services a student with a disability must receive.²⁴ The IEP must be developed, and services must be provided in accordance with four vital mandates of IDEA: to prepare children for employment and independent living, to provide education in the least restrictive environment, to provide related services, and to cooperate with other agencies responsible for the provision of behavioral health services for children.²⁵

1. Preparing for Employment and Independent Living

The rights of children with disabilities to special education are not limited to traditional academic components. IDEA has a broad definition of education, including a duty to provide education to address behavioral issues and skills

17. 29 U.S.C.A. § 705(20)(B); 34 C.F.R. 104.3(j)(2) (ii).

18. 34 C.F.R. §§ 104.33(a), 104.34(a) (2001); *see also* EILEEN L. ORDOVER, EDUCATION RIGHTS OF CHILDREN WITH DISABILITIES: A REVISED & UPDATED PRIMER FOR ADVOCATES 47-50 (Center for Law and Education 2001).

19. *See* 34 C.F.R. §§ 104.33(a), 104.34(a) (2001).

20. The State can delegate this authority to the State Educational Agency (SEA). SEA is defined as "the State board of education or other agency or officer primarily responsible for the State supervision of public elementary and secondary schools." 20 U.S.C.A. § 1401(28) (West 2000).

21. 20 U.S.C.A. § 1414(a)(1)(A) (West 2000).

22. 20 U.S.C.A. § 1414(a)(1)(B) (West 2000).

23. *Honig v. Doe*, 484 U.S. 305, 311 (1988).

24. 20 U.S.C.A. § 1414(d)(1)(A) (West 2000), 34 C.F.R. § 300.340(a) (2001).

25. Many states also have special education laws, which, in many cases, provide increased protection for children with disabilities. *See, e.g.*, CAL. EDUC. CODE § 56000 (West 1989).

necessary for transition to adult life.²⁶ Learning the skills necessary to function is an explicit directive of the IDEA, which specifically states that education must be designed to "prepare them for employment and independent living."²⁷ IEPs must include behavioral goals. Those goals have been interpreted by courts as "not limited to academic benefits, but to also include behavioral and emotional growth."²⁸ Education must provide a sufficient opportunity to learn behavior control skills.²⁹

IDEA was specifically amended in 1997 to require the IEP to consider "strategies, including positive behavioral interventions, [and] strategies and supports to address that behavior."³⁰ The 1997 amendments to IDEA also clarified the importance of preparation for adult life and transition services.³¹ Transition services are a coordinated set of activities based on the individual student's needs, taking into account the student's preferences and interests; they include "instruction, related services, community experiences, the development of employment and other post-school adult living objectives; and if appropriate, *acquisition of daily living skills* and functional vocational evaluation."³² The plan must include specific goals and address the individual needs of the child, and must not be limited to vocational assessments and goals.³³ The related regulations require that the IEP for each student with a disability include, beginning at age fourteen or younger, a statement of the student's transition service needs, which must be updated annually.³⁴ Beginning at no later than age sixteen, the IEP must also include a statement of interagency responsibilities or any linkages.³⁵

The Office of Special Education Programs (OSEP), which provides guidance to State Education Agencies on monitoring the implementation of all the provisions of IDEA, places "the highest priority on compliance with those IDEA requirements that have the strongest relationship with improved services and

26. See 20 U.S.C.A. § 1400 (d)(1)(A) (West 2000) (special education must prepare students for "employment and independent living").

27. 20 U.S.C.A. § 1400 (d)(1)(A) (West 2000); 34 C.F.R. § 300.1 (2001); see also *Polk v. Central Susquehanna Intermediate Unit*, 853 F.2d 171, 176 (3d Cir. 1988), *cert denied*, 488 U.S. 1030 (1989). See generally EILEEN L. ORDOVER, *EDUCATION RIGHTS OF CHILDREN WITH DISABILITIES: A REVISED & UPDATED PRIMER FOR ADVOCATES* 47-51 (Center for Law and Education, 2001).

28. *County of San Diego v. California Special Educ. Hearing Office*, 93 F.3d 1458, 1468 (9th Cir. 1996).

29. *Chris D. v. Montgomery County Bd. of Ed.*, 753 F.Supp. 922, 933 (M.D. Ala. 1990).

30. 20 U.S.C.A. § 1414(d)(3)(B) (West 2001).

31. 34 C.F.R. § 300.29(a)(3).

32. *Id.* (emphasis added) ("Transition services for students with disabilities may be special education, if provided as specially designed instruction, or related services, if required to assist a student with a disability to benefit from special education.").

33. See *E. Pa. Sch. Dist. v. Scott B.*, 1999 WL 178363, at *6 (E.D. Pa. 1999) (finding transition plan woefully inadequate for failing to include other aspects of transition planning including transportation, recreation and how the child would meet his personal needs).

34. 34 C.F.R. § 300.347(b)(1).

35. 34 C.F.R. § 300.347(b)(2).

results for students with disabilities and their families."³⁶ In setting its priorities, the OSEP has included transitional planning requirements among the regulations because they have the strongest links to improved results.³⁷

2. Providing Education in the Least Restrictive Environment

The state must ensure that special education is provided in the least restrictive environment.³⁸ Students must be educated in regular classrooms "to the maximum extent appropriate."³⁹ The IDEA provides that "removal of children with disabilities from the regular educational environment occurs only when the nature of severity of the disability of a child is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily."⁴⁰ The 1997 amendments to IDEA strengthened and clarified the statutory preference that children with disabilities be educated in the regular classroom with non-disabled children by specifically requiring that the IEP include an explanation of the extent to which the child will *not* participate in regular classes and activities.⁴¹ Federal law further provides that "unless the IEP requires some other arrangement, the school system shall ensure that a child is educated in the school that he or she would attend if nondisabled,"⁴² and that the placement be as "close as possible to the child's home."⁴³

IDEA does not require that children with severe behavioral difficulties continue to be educated in classrooms where the child cannot benefit from education. The statute does, however, state a federal intention to have children receive whatever services they need to be served in the least restrictive environment, regardless of the severity of the child's disability.⁴⁴ For some

36. U.S. DEPARTMENT OF EDUCATION, CH. 5, EIGHTEENTH ANNUAL REPORT TO CONGRESS ON THE IMPLEMENTATION OF THE INDIVIDUALS WITH DISABILITIES ACT 1 (1996), *available at* <http://www.ed.gov/pubs/OSEP96AnlRpt/chap5.html>.

37. *Id.*; see also U.S. DEPARTMENT OF EDUCATION, OFFICE OF SPECIAL EDUCATION PROGRAMS, CONTINUOUS IMPROVEMENT MONITORING PROCESS: 2000-2001 MONITORING MANUAL (2000), *available at* <http://www.dssc.org/frc/monitor/manual00.pdf>.

38. 20 U.S.C.A. § 1412(5)(A) (West 2000).

39. *Id.*

40. 20 U.S.C.A. § 1412(5)(A) (West 2000) (Section §504 of the Rehabilitation Act of 1973 also requires that schools provide the services to children necessary for them to be educated in the least restrictive environment, specifically stating that children must be educated in a regular classroom, unless the school system can demonstrate that "the education of the person in the regular environment either through the use of supplementary aids and service cannot be achieved satisfactorily.").

41. 20 U.S.C.A. § 1414(d)(1)(A)(iv) (West 2000).

42. 34 C.F.R. § 300.552(c) (2001).

43. 34 C.F.R. § 300.552(b)(3) (2001).

44. *Daniel R.R. v. State Bd. of Educ.*, 874 F.2d 1036 (5th Cir. 1989) (judicial preference for "mainstreaming"); *Oberti v. Bd. of Educ.*, 995 F.2d 1204 (3d Cir. 1993) (student with behavioral problems could be successfully educated in the regular education department with supplementary aids and services); *Sacramento City Sch. Dist. v. Rachel H.*, 12 F.3d 1398 (9th Cir. 1994), *cert denied*, 512 U.S. 1207 (1994) (full-time regular education with a part time aide is an appropriate placement for a child with an I.Q. of 44).

students, a residential placement may well be the least restrictive,⁴⁵ and the school system must provide the educational program within the residential placements.⁴⁶

3. Securing Related Services

The states must also secure related services for children in special education. Federal law clearly states that " 'free appropriate public education' means special education and related services."⁴⁷ Related services are "such developmental, corrective, and other supportive services . . . as may be required to assist a child with a disability to benefit from special education"⁴⁸ Related services include counseling services,⁴⁹ psychological services,⁵⁰ and social work services in schools.⁵¹ Each public agency must ensure that a continuum of alternative placement is available to meet the needs of children with disabilities for special education and related services.⁵²

4. Coordinating Among Agencies

IDEA requires school systems to coordinate with other federal programs, such as Medicaid, to finance and deliver services to children with disabilities.⁵³ The 1997 Amendments to IDEA made it clear that other public agencies must provide services that are necessary for ensuring a free and appropriate public education to children with disabilities.⁵⁴ IDEA now specifically states that agencies responsible for providing or paying for services related to special education, including transition and supplementary aids and services "shall fulfill that obligation or responsibility, either through contract or other arrangement."⁵⁵ While the statute indicates that the local educational agency is the payer of last resort,⁵⁶ the statute mandates that interagency agreements or other mechanisms for interagency coordination be in effect between each public agency responsible for providing related services,⁵⁷ and that the school district provide necessary related services, for which it can then seek reimbursement.⁵⁸

45. *Bd. of Educ. v. Diamond*, 808 F.2d 987, 992 (3d Cir. 1986).

46. *Id.* at 992.

47. 20 U.S.C.A. § 1401(8)(A-D) (West 2000).

48. 20 U.S.C.A. § 1401(22) (West 2000).

49. 34 C.F.R. §§ 300.24(a), 300.24(b)(2) (West 2000).

50. 34 C.F.R. §§ 300.24(a), 300.24(b)(9) (West 2000).

51. 34 C.F.R. §§ 300.24(a), 300.24(b)(13) (West 2000).

52. 34 C.F.R. § 300.551(a) (2001).

53. 20 U.S.C.A. § 1412(a)(12) (West 2000).

54. 20 U.S.C.A. § 1412(a)(12)(B)(i) (West 2000).

55. 20 U.S.C.A. § 1412(a)(12)(B)(i) (West 2000).

56. 20 U.S.C.A. § 1412(a)(12)(A)(ii) (West 2000).

57. 20 U.S.C.A. § 1412(a)(12)(A)(i) (West 2000).

58. 20 U.S.C.A. § 1412(a)(12)(B)(ii) (West 2000).

Despite this clarifying legislation, the boundaries between programs and the methods by which agencies coordinate are not entirely clear. A 1999 study by the Government Accounting Office (GAO) identified concerns about the levels of coordination and the ability of interagency agreements to effectively address those concerns, as well as the need to clarify the mechanisms for securing services and reimbursements.⁵⁹

Federal law also specifically requires coordination of services for transition planning. As discussed above, beginning at no later than age sixteen, the IEP must not only include a statement of transition service needs, but also if appropriate, a statement of the interagency responsibilities or any linkages.⁶⁰ The planning must include appropriate individuals from outside the school system in the development and implementation of the IEP⁶¹ "at the discretion of the parent or the agency, other individuals who have knowledge or special expertise regarding the child, including related services personnel."⁶² Further, "the public agency also shall invite a representative of any other agency that is likely to be responsible for providing or paying for transition services."⁶³

Once Jesse was identified as eligible for special education, the public school was required to design an educational program that would prepare him for employment and independent living, a program that included strategies and supports to address behavior control skills. Jesse had a right to be educated at a school as close as possible to his home. The school system was responsible for providing supportive services, including psychological services or behavioral management, where necessary to help him benefit from his education. The public education system was required to coordinate services with other federal programs, such as Medicaid, throughout Jesse's childhood, as well as to identify and coordinate efforts in the development of a plan for his transition to adulthood and independent living. Jesse's experience demonstrates the failure of the school system to comply with these vital federal mandates.

B. Jesse's Early Life and the Missed Opportunity to Provide Appropriate Education to Jesse

Jesse Martinez was born as the fourth of six children to Patrick Martinez and his wife on January 9, 1981, in the San Jose neighborhood of Albuquerque, New Mexico. A year later, his mother began to show signs of adult onset schizophrenia. She was in and out of mental hospitals until Jesse was approximately five

59. GOVERNMENT ACCOUNTING OFFICE, REPORT NO. HEHS-00-20, MEDICAID AND SPECIAL EDUCATION: COORDINATION OF SERVICES FOR CHILDREN WITH DISABILITIES IS EVOLVING (1999).

60. 34 C.F.R. § 300.347(b)(2)(2001).

61. RONALD M. HAGER, ASSISTIVE TECHNOLOGY FUNDING & SYSTEMS CHANGE PROJECT/NATIONAL ASSISTIVE TECHNOLOGY ADVOCACY PROJECT, FUNDING OF ASSISTIVE TECHNOLOGY, THE PUBLIC SCHOOL'S SPECIAL EDUCATION SYSTEM AS A FUNDING SOURCE: THE CUTTING EDGE 16 (1999).

62. 34 C.F.R. § 300.344(a)(6) (2001).

63. 34 C.F.R. § 300.344(b)(3)(i) (2001).

years old. One day, Mr. Martinez came home to find her throwing furniture out of the window. Jesse's mother was committed to the state mental hospital and left the family, never to return during Jesse's lifetime.

Jesse cried constantly for his mother. When Mr. Martinez took him to pre-school,⁶⁴ he would cry uncontrollably. The preschool staff told Mr. Martinez that Jesse was terrified that his father, too, would abandon him. Jesse was a "very loveable and affectionate child,"⁶⁵ but he began to act out in school. By the time he was in kindergarten, Jesse was demonstrating aggressive behavior.

Jesse's challenges at school were compounded by problems at home. Mr. Martinez was doing the best that he could as a single father of six children. His challenges were significantly complicated by Jesse's mental health needs, as well as the mental health needs of several of his other children.

In first grade, when Jesse was seven years old, he was found eligible for special education as "Behaviorally Disordered."⁶⁶ In second grade, he was placed in a more intensive level of special education.⁶⁷ By fourth grade, Jesse had lower work speed, lower oral language skills and lower reading math and written skills than the rest of the class.⁶⁸ He functioned at a first grade level. He did not know subtraction.⁶⁹ Jesse was identified at that time as Learning Disabled.⁷⁰ In the classroom, Jesse exhibited outbursts of anger, fought with other children and lacked self-control.⁷¹ By the time Jesse was nine years old, counseling support at the school was recommended.⁷²

1. Failure to Provide Preparation for Employment and Independent Living

Rather than providing counseling and helping Jesse to prepare for adult life and independent living, the schools relied on Mr. Martinez to come and pick Jesse up when he acted out in school. Jesse soon learned to act out so that the school would call his father. In fifth or sixth grade, Jesse ate marbles at school. He then said to the teacher, "I guess you are going to call my Dad." Mr. Martinez told officials at Jesse's middle school that he would come and get Jesse, but that it was not going to help Jesse learn to address his difficulties in school. Mr. Martinez asked the school to bring in a counselor to deal with the situations at the time they arose. But counseling was not provided and for years the schools

64. Jesse attended a wonderful, therapeutic preschool in Albuquerque, operated by the Peanut Butter & Jelly Family Services, Inc.

65. NEW MEXICO DEPARTMENT OF HEALTH, SEQUOYAH ADOLESCENT TREATMENT CENTER, INTEGRATED SUMMARY (July 30, 1997).

66. ALBUQUERQUE PUBLIC SCHOOLS, CONFIDENTIAL DIAGNOSTIC REPORT 2 (Sept. 24, 2000) (on file with the Georgetown Journal on Poverty Law & Policy).

67. *Id.*

68. *Id.* at 5.

69. *Id.* at 9.

70. *Id.*

71. *Id.* at 9-10.

72. *Id.* at 11.

continued to rely on Mr. Martinez to come and remove Jesse whenever problems arose.

One day when Mr. Martinez was at Jesse's middle school attending an IEP meeting, he saw five gang members confronting Jesse in the hallway of the school. Mr. Martinez and the entire IEP group saw the confrontation; however, no one attempted to help Jesse address the situation. Mr. Martinez intervened and prevented the five boys from fighting with Jesse, but it was evident that no one was helping Jesse learn the behavioral skills necessary to survive in his challenging world.

By the time Jesse was sixteen, he was entangled in the juvenile justice system and was sent to a highly structured residential treatment facility for violent juveniles.⁷³ Jesse was able to make academic progress in the structured environment. However, at the time of his second and final discharge from that facility in February 1999, the plans for transitioning Jesse into the community were woefully inadequate. The Individualized Education Program that was done on the day of Jesse's ultimate discharge stated that "alternative placements will be explored."⁷⁴ The IEP form includes the question, "[w]hat are we going to do to help Jesse receive an appropriate education?"⁷⁵ The answer indicates that the school system would provide four hours of homebound education, explore alternative programs and "continue to transition case manage."⁷⁶ The remaining four and a half pages of the IEP's space provided for the discussion of strategies for an appropriate education are blank.⁷⁷

At that time, Jesse's most recent IQ test had shown that Jesse had mental retardation,⁷⁸ and a second grade reading level. Yet, upon the discharge from the highly structured treatment environment where he was able to progress academically, he was sent to a local community college. The first day of class the teacher showed the movie "One Flew over the Cuckoo's Nest." Fortunately, the irony and the plot were lost on Jesse. When asked what the movie was about, and how he felt about it, he stated that he did not understand the movie but that it was "okay."⁷⁹

Jesse never graduated from high school. He received special education while incarcerated in the juvenile detention center (the D-Home), except for the many periods when he was "off privileges" and therefore not permitted to go to school. No apparent efforts were made to provide him with education when he was

73. NEW MEXICO DEPARTMENT OF HEALTH, SEQUOYAH ADOLESCENT TREATMENT CENTER, DISCHARGE SUMMARY (Dec. 23, 1997).

74. ALBUQUERQUE PUBLIC SCHOOLS, SPECIAL EDUCATION, INDIVIDUALIZED EDUCATION PROGRAM (Feb. 22, 1999) (on file with the Georgetown Journal on Poverty Law & Policy).

75. *Id.*

76. *Id.*

77. *See id.*

78. NEW MEXICO DEPARTMENT OF HEALTH, SEQUOYAH ADOLESCENT TREATMENT CENTER, INTEGRATED SUMMARY 1 (July 30, 1997) (on file with the Georgetown Journal on Poverty Law & Policy).

79. Interview with Jesse Martinez, Albuquerque, N.M. (Feb. 23, 1999).

ultimately illegally transferred to the adult jail.⁸⁰

Jesse had a right to receive assistance in learning skills necessary to prepare him for employment and independent living.⁸¹ This assistance should have been consistently provided for him throughout his life so that he could have had a chance to learn the skills necessary to cope with his disabilities, and perhaps avoid becoming entangled in the juvenile justice system. Despite the needs stated in the school's own diagnostic reports and Mr. Martinez's chronic pleas over the first dozen years of Jesse's education for the school to provide instruction to Jesse at the time that he acted out, counseling services were not provided to Jesse.

Nobody helped develop any meaningful transition plan for Jesse either. Despite the clear laws requiring transition planning,⁸² the transition plan was inadequate. Mr. Martinez is unaware of any vocational assessment performed during Jesse's lifetime.

2. Failure to Provide Education in the Least Restrictive Environment

The public education system has a responsibility to provide appropriate education to all students, regardless of the severity of their disabilities, and cannot discriminate on the basis of mental illness or disability. Every effort must be made to educate children in their neighborhood school with their non-disabled peers. Thus, it was not permissible for the school system to move Jesse out of his neighborhood without making every effort to educate him in his regular classroom, nor was it permissible for the school system to merely declare that Jesse was severely mentally ill, and therefore that it could not provide adequate education.

By seventh grade, Jesse was in the most intensive level of special education at middle school.⁸³ His special education teacher stated that Jesse was making some headway in learning to control his temper.⁸⁴ But Jesse continued to demonstrate "characteristics of a seriously emotionally/ behaviorally disturbed and specific learning disabled child."⁸⁵ "Jesse appears to exhibit inappropriate types of behavior or feelings under normal circumstances. These behaviors have occurred to a high degree over a long period of time and have adversely affected Jesse's educational performance."⁸⁶

The school threatened to move Jesse to a school as far away from his neighborhood in Albuquerque as possible, both culturally and geographically. Mr. Martinez was very clear that Jesse would be extremely disoriented if he had

80. See *infra* Section 4.

81. 20 U.S.C.A. § 1400 (d)(1)(A) (West 2000); 34 C.F.R. § 300.1(a) (2001); see *supra* Section II.A.1.

82. 20 U.S.C.A. § 1414(1)(A)(vii)(II) (West 2001); see also *infra* Section II.A.1.

83. See ALBUQUERQUE PUBLIC SCHOOLS, MULTIDISCIPLINARY EVALUATION REPORT (Apr. 12, 1994).

84. *Id.* at 1.

85. *Id.* at 6.

86. *Id.*

to go to school in a different neighborhood. He told school officials at Jesse's middle school that the school was reputed to have one of the best special education programs in the city, and pleaded with the school to address Jesse's problems in the community where Jesse lived.⁸⁷ The school officials agreed to keep Jesse at the local school, but warned that after one more incident Jesse would be moved.

Within weeks, Jesse was sent from full time middle school to a school far from his home where he received only one hour of education a day. Jesse was threatened by the new environment and was completely lost in the program. The kids were violent and the school was out of Jesse's neighborhood, so he did not feel comfortable there. Behaviorally, Jesse refused to go to school altogether. Academically, Jesse had completely stopped functioning.

Federal law required that Jesse be educated as close to home as possible.⁸⁸ However, Jesse was transferred out of his neighborhood school and was overwhelmed. He ceased to participate in the educational process entirely. A subsequent evaluation found that:

[e]ven the most intensive APS [Albuquerque Public Schools] program for seriously Emotionally/Behaviorally Disturbed Students probably would not be helpful at this time. Jesse needs intensive and sustained psychiatric hospitalization and psychotropic medication for his mood instability. A possible thought disorder should be evaluated Jesse is at extreme risk and mentally ill.⁸⁹

The evaluation also found Jesse "too unstable to be served on a public school campus," and recommended a referral to residential treatment.⁹⁰ The report also reflects that Mr. Martinez complained that Jesse had not seen a psychologist before, and that there was no follow-up.⁹¹ Mr. Martinez and the evaluator expressed concern that Jesse would end up incarcerated in the juvenile justice system,⁹² but there was no concerted effort made to help Jesse avoid this fate.

If the school had provided sufficient classroom support in Jesse's neighborhood school, and that support did not permit Jesse to learn, then the public education system should have assisted in securing related services for Jesse, including residential treatment.

87. Mr. Martinez had sought the assistance of an advocate from a parents' group, Parents for Behaviorally Different Children. He had asked that the advocate accompany him to the IEP meeting to address the threat to move Jesse because he feared that he would not be able to adequately protect Jesse's rights. The school officials gave the advocate a different date for the IEP meeting and she did not appear to assist Mr. Martinez.

88. 34 C.F.R. § 300.552(b)(3) (2001).

89. ALBUQUERQUE PUBLIC SCHOOLS, PSYCHOEDUCATIONAL NEEDS EVALUATION 6-7 (Nov. 6, 1996).

90. *Id.* at 7.

91. *Id.* at 4.

92. *Id.* at 7.

3. Failure to Secure Related Services for Jesse

Jesse was not provided with the related services necessary to help him learn the skills he needed to survive. The school's reliance on Mr. Martinez to come to the school and remove Jesse was an evasion of its responsibility to provide behavioral management specialists, or other teacher's aids who might have been able to assist Jesse to benefit from his education and develop appropriate behavior.

The school system did not provide any psychoeducational evaluations or assistance in securing them until Jesse was fifteen. When Jesse started high school, Mr. Martinez independently sought a psychiatric evaluation for Jesse. However, there was a six-month waiting list. Mr. Martinez continued to attempt to get Jesse educated by taking him to school, but Jesse continued to struggle. Jesse could not read. He could still not subtract or understand the basic materials. Nonetheless, he was placed in a 9th grade class, where it was easier for Jesse to be disruptive than to be humiliated for his academic weaknesses.

Out of desperation, Mr. Martinez eventually refused to send any of his children to school until psychiatric evaluations were performed. The Psychoeducational Needs Evaluation that was eventually performed concluded that "Jesse's psychiatric problems first must be managed medically before he can be served adequately in a public educational setting."⁹³ However, the school system provided no assistance in securing the medical management, residential treatment or other related services that the school system's evaluator found to be necessary for Jesse to benefit from his education.

4. Coordination Between Agencies Was Not Discernable

Despite clear federal mandates requiring the public education system to coordinate with other agencies to provide services necessary to help children benefit from their education, no coordination was evident in Jesse's case. Rather than coordinating efforts with medical and juvenile justice service providers, the special education administrators eventually told Mr. Martinez that the educational system was simply not prepared to address a student with Jesse's level of needs. They recommended long-term, residential psychiatric treatment for Jesse, but there were no apparent efforts to help Mr. Martinez secure those related services. As Jesse grew older and was released from treatment centers, no educational services whatsoever were provided. Rather, the gap remained between Jesse's clear statutory rights to free appropriate public education, and the actual services that he received.

93. ALBUQUERQUE PUBLIC SCHOOLS, PSYCHOEDUCATIONAL NEEDS EVALUATION 7 (Nov. 6, 1996).

III. MEDICAID IS REQUIRED TO PAY FOR ALL MEDICALLY NECESSARY SERVICES FOR POOR CHILDREN

The rights of poor children extend to all "medically necessary services," and to "such other necessary health care . . . to correct or ameliorate defects and physical and mental illnesses"⁹⁴ Children have these rights under the "Medicaid Act,"⁹⁵ which includes a program called Early Periodic Screening Diagnosis and Treatment (EPSDT).⁹⁶ These statutes provide expansive definitions of the services and list the strict, detailed requirements that states must follow to participate in the federal Medicaid program. However, as Jesse's experience demonstrates, children often do not receive the range of services to which they are entitled.

A. Medicaid and Early Periodic Screening Diagnosis and Treatment (EPSDT) Was Enacted to Address Health of Poor and Children

Medicaid is a federal medical insurance program for the poor and disabled.⁹⁷ The program is designed to enable states to furnish medical assistance on behalf of dependent children, aged, blind, and disabled people with insufficient means to meet the costs of medically necessary services.⁹⁸ The other purpose of the Medicaid program is to enable states to furnish "rehabilitation and other services to help such families and individuals attain or retain capability for independence or self care."⁹⁹

Medicaid was enacted in 1965 to provide access to health care for poor people who had previously been deprived of medically necessary services.¹⁰⁰ To address the fact that more than 3.5 million children under five were failing to receive medical assistance, the program was expanded to include the Early Periodic Screening Diagnosis and Treatment Program (EPSDT) in 1967.¹⁰¹ Congress envisioned not only the provision of reimbursement for expenditures on child health, but also an aggressive search for early detection of child health problems.¹⁰²

B. Mandates to the States

The federal program is voluntary for the states.¹⁰³ Every state, however, has

94. 42 U.S.C.A. §§ 1396d(r)(1)(B), 1396a(43)(B) (West 2000).

95. 42 U.S.C.A. § 1396 (West 2000).

96. 42 U.S.C.A. § 1396d(r) (West Supp. 2001); 42 U.S.C.A. § a(a)43A-D (West Supp. 2001).

97. 42 U.S.C.A. § 1396 (West Supp. 2001).

98. *Id.*

99. 42 U.S.C.A. § 1396 (West Supp. 2001).

100. *Id.*

101. President Lyndon B. Johnson, Address to Congress (Feb. 8, 1967); 42 U.S.C.A. §§ 1396a(a)(10)(A), 1396a(a)(43), 1396d(4)(B), 1396(r) (West Supp. 2001).

102. *Stanton v. Bond*, 504 F.2d 1246, 1251 (7th Cir. 1974).

103. 42 U.S.C.A. § 1396 (West Supp. 2001) (making funds available to states with approved State plans for medical assistance).

elected to participate in Medicaid to benefit from the significant portion of the costs of medical assistance that will be paid by the federal government.¹⁰⁴ For example, in New Mexico, the federal government pays approximately 73% of all Medical Assistance service costs, and the state pays the remaining 27% of the costs.¹⁰⁵

Once a state elects to participate, it must comply with the federal statutory scheme and regulations promulgated by the Secretary of Health and Human Services.¹⁰⁶ The state is required to submit a detailed plan to the federal government setting forth how it intends to comply with the extensive and detailed requirements.¹⁰⁷ The state plan must include many assurances to the federal government,¹⁰⁸ including the following five mandates: (1) coverage of medically necessary services,¹⁰⁹ (2) Early Periodic Screening Diagnosis and Treatment (EPSDT),¹¹⁰ (3) case management,¹¹¹ (4) the protection of specific due process rights for Medicaid beneficiaries,¹¹² and (5) coordination among state agencies of efforts to provide medical services to poor children.¹¹³ These five important mandates are described in more detail in this section, and serve as the basis for the analysis of the impact of managed care on Medicaid, as well as the failure to provide necessary services to Jesse.

1. States Must Provide Medical Services in the Amount, Duration and Scope Necessary to Maximally Reduce Mental Disabilities and Restore Individuals to the Best Possible Functional Level

The definition of medical assistance is broad. Each state plan must include a provision that medical assistance "shall be furnished with reasonable promptness to all eligible individuals."¹¹⁴ The definition includes payments for all or part of

104. The exact percentage of the payments depends on state population as set forth in 42 U.S.C.A. § 1396d(b) (West Supp. 2001).

105. 42 U.S.C.A. § 1396d(b) (West Supp. 2001).

106. See, e.g., *Christy v. Ibarra*, 826 P.2d 361 (Colo. Ct. App. 1991); *Morgan v. Idaho Dep't of Health and Welfare*, 813 P.2d 345 (Idaho 1991); *Rye Psychiatric Hosp. Ctr., Inc. v. Surles*, 777 F. Supp. 1142 (S.D.N.Y. 1991); *Conn. Hosp. Ass'n v. O'Neill*, 793 F. Supp. 47 (D. Conn. 1992).

107. 42 U.S.C.A. § 1396a (West Supp. 2001). The plans are reviewed, and ultimately approved, or rejected, by the federal Centers for Medicare and Medicaid Services (CMS), formerly known as the Health Care Financing Administration (HCFA).

108. See 42 U.S.C.A. § 1396 (West Supp. 2001); 42 C.F.R. § 430.0-104 (2001); JANE PERKINS AND SARAH SOMERS, NATIONAL HEALTH LAW PROGRAM (NHELP), AN ADVOCATE'S GUIDE TO THE MEDICAID PROGRAM 2.3-2.5 (2001).

109. 42 U.S.C.A. § 1396d(a)(13) (West Supp. 2001).

110. 42 U.S.C.A. § 1396a(a)(43)(A-D) (West 2002).

111. 42 U.S.C.A. § 1396d(a)(19) (West Supp. 2001).

112. 42 U.S.C.A. § 1396a(a)(3) (West Supp. 2001); 42 C.F.R. §§ 431.200 (2001).

113. See 42 U.S.C.A. § 1396a(a)(11)(A) (West Supp. 2001); 42 C.F.R. § 441.61(c) (2001); HEALTH CARE FINANCING ADMINISTRATION (HCFA) STATE MEDICAID MANUAL § 5230-5230.2, available at <http://cms.hhs.gov/manuals/pub45pdf/smm5t.pdf>.

114. 42 U.S.C.A. § 1396a(A)(8) (West 2002).

the costs of "diagnostic, screening, preventive, and rehabilitation services including any medical or remedial services recommended by a physician or other licensed practitioner of the healing arts within the scope of their practice under State law for the maximum reduction of physical or mental disability and restoration of an individual to the best possible functional level" ¹¹⁵

The Medicaid regulations require participating states to provide all medically necessary services in sufficient amount, duration and scope to effectively address the condition. ¹¹⁶ These regulations are to be liberally construed in favor of the intended beneficiaries of the Medicaid Program. ¹¹⁷ The United States Supreme Court, in an opinion on a different issue, stated that "serious questions might be presented if a state Medicaid plan excluded necessary medical treatment from its coverage." ¹¹⁸

Importantly, Congress intended for the treating physician to have broad discretion in determining which services are medically necessary for a patient. ¹¹⁹ Therefore, when doctors find that services are medically necessary, the state must provide payment for those services. States must assure that payments are sufficient to enlist enough providers so that care and services are available under the plan at least to the extent that such care and services are available to the general population in the geographic area. ¹²⁰

2. States Must Provide Periodic Screening and the Services Necessary to Ameliorate Conditions Identified in Children

Under federal law, the state Medicaid plan must provide for early, periodic screening; diagnosis; and treatment for all eligible children under the age of twenty-one. ¹²¹ Early periodic screening, diagnosis and treatment require comprehensive screenings and treatment for conditions discovered during the screens. ¹²² Screening services must be provided at regular intervals to determine whether the child has certain physical or mental illnesses or conditions. ¹²³ The screens must include a comprehensive health and developmental history, and assessments of both physical and mental health development. ¹²⁴ The state must provide "such

115. 42 U.S.C.A. § 1396d(a)(13) (West Supp. 2001) (emphasis added).

116. 42 C.F.R. § 440.230 (2001).

117. *Visser v. Taylor*, 756 F. Supp. 501, 507 (D. Kan. 1990).

118. *Beal v. Doe*, 432 U.S. 438, 444 (1977).

119. S. REP. NO. 89-404, pt. 1 (1965), reprinted in 1965 U.S.C.A.N. 1943, 1986 ("[T]he physician is to be the key figure in determining utilization of the health services."); see also *Weaver v. Reagan*, 886 F.2d 194, 200 (8th Cir. 1989); *Pinneke v. Preisser*, 623 F.2d 546, 550 (8th Cir. 1980).

120. 42 U.S.C.A. § 1396a(30)(A) (West Supp. 2001).

121. 42 U.S.C.A. § 1396a(a)(10) (West Supp. 2001); 42 U.S.C.A. § 1396d(a)(xii)(4)(B) (West Supp. 2001) (defining "medical assistance" as including "early and periodic screening, diagnostic, and treatment services").

122. 42 U.S.C.A. § 1396d(r) (West Supp. 2001).

123. 42 U.S.C.A. § 1396d(r)(1)(A) (West Supp. 2001).

124. 42 U.S.C.A. § 1396d(r)(1)(B)(i) (West Supp. 2001); 42 C.F.R. § 440.40(b) (2001).

other necessary health care, diagnostic services, treatment . . . to correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services, whether or not such services are covered under the state plan."¹²⁵ This includes services necessary to prevent, arrest, or delay the development or progression of a mental or physical illness, to prevent relapse, and to maximally reduce physical or mental disabilities that are chronic conditions.¹²⁶

The state must not only provide medical services to children who request them. It must engage in an aggressive search to identify children's needs at an early age.¹²⁷ The state must make affirmative efforts to inform all eligible persons in the state who are under the age of twenty-one of the availability of early periodic, screening, diagnosis and treatment.¹²⁸ It must also provide assistance to families in arranging for screening services, and arranging for corrective treatment, when the need for services is identified.¹²⁹ The regulations require the states to provide scheduling and transportation assistance to families.¹³⁰

To monitor compliance with this important program, the Secretary of Health and Human Services is required to set annual participation goals for each state to measure the level of participation of individuals covered under the state plan, and states are required to report their progress in meeting those participation goals.¹³¹ In 1990, the Secretary set participation goals, requiring the states to demonstrate that by 1995, 80% of eligible children under twenty-one were receiving the medical examinations required by the EPSDT program.¹³²

3. Case Management Services

The state plan may also provide for coverage of case management services.¹³³ These are services that will assist individuals eligible under the plan in gaining access to needed medical, social, educational, and other services.¹³⁴ The state plan is not required to provide case management to all adults. However, some states, including New Mexico, have elected to provide case management services to Medicaid beneficiaries.¹³⁵ And, under EPSDT, states must provide "other

125. 42 U.S.C.A. § 1396d(r)(5) (West Supp. 2001); 42 C.F.R. § 441.56(b)(1) (2001).

126. See 42 U.S.C.A. § 1396d(r)(5) (West Supp. 2001); 42 C.F.R. § 440.130 (c)(1) (2001).

127. *Stanton v. Bond*, 504 F.2d at 1246, 1251 (7th Cir. 1974).

128. 42 U.S.C.A. § 1396a(a)(43)(A) (West Supp. 2001); C.F.R. 441.56(a) (2001).

129. 42 U.S.C.A. §§ 1396a(a)(43)(B)-(C) (West Supp. 2001), 42 U.S.C.A. § 1396d(a)(4)(B) (West Supp. 2001).

130. 42 C.F.R. § 440.230 (2001); see also *Salazar v. District of Columbia*, 954 F. Supp. 278, 280 (1996).

131. 42 U.S.C.A. § 1396d(r) (West Supp. 2001).

132. HEALTH CARE FINANCING ADMINISTRATION, STATE MEDICAID MANUAL § 5360, available at <http://cms.hhs.gov/manuals/pub45pdf/smm5t.pdf>.

133. 42 U.S.C.A. § 1396d(a)(19) (West Supp. 2001).

134. 42 U.S.C.A. § 1396n(g)(2) (West Supp. 2001).

135. Regulations now codified at N.M. ADMIN. CODE tit.8 ch.305 pt.7 (2003).

necessary services whether or not covered by the state plan.”¹³⁶ The provisions of the Medicaid Act regarding case management contemplate that case managers would be provided to children with chronic mental illness, as it provides that the state “may limit the case managers available with respect to case management services for eligible individuals with developmental disabilities or with chronic mental illness in order to ensure that the case managers for such individuals are capable of ensuring that such individuals receive needed services.”¹³⁷

4. States Must Provide Fair Hearings

The statutory due process protections for Medicaid beneficiaries are broad and clear. The state plan must provide for granting a fair hearing whenever claims for medical assistance have been denied, reduced or delayed.¹³⁸ The related regulations require that a provider give timely and adequate notice of proposed action to terminate, discontinue or suspend services.¹³⁹ The required notice of a proposed action related to a claim for medical assistance must include the reasons for the action, the specific regulations that support the action, and an explanation of recipients' right to a hearing.¹⁴⁰

5. State Agencies Must Cooperate with Other State Agencies

The State plan must provide for “entering into cooperative arrangements with the state agencies responsible for administering or supervising the administration of health services, and vocational rehabilitation services in the State looking toward maximum utilization of such services in the provision of medical assistance under the plan.”¹⁴¹ Federal law requires that the provision of health services be coordinated with the state agency that is responsible for providing services to abused, neglected and delinquent children.¹⁴² In New Mexico, the responsible agency is the Children Youth and Families Department.¹⁴³ States must also “provide such safeguards as may be necessary to assure . . . such care and services will be provided, in a manner consistent with simplicity of administration and the best interest of the recipients.”¹⁴⁴

136. HEALTH CARE FINANCING ADMINISTRATION, STATE MEDICAID MANUAL § 5122, available at <http://cms.hhs.gov/manuals/pub45pdf/smm5t.pdf>; see also 42 U.S.C.A. § 1396a(a)(11)(B) (West Supp. 2001).

137. 42 U.S.C.A. § 1396n(g)(1) (West Supp. 2001).

138. 42 U.S.C.A. § 1396a(a)(3) (West Supp. 2001); 42 C.F.R. §§ 431.200, 431.210 (2001).

139. 42 C.F.R. § 435.919 (2001).

140. 42 C.F.R. § 431.210 (2001).

141. 42 U.S.C.A. § 1396a(a)(11)(A) (West Supp. 2001); 42 C.F.R. § 441.61 (2001); HEALTH CARE FINANCING ADMINISTRATION (HCFA) STATE MEDICAID MANUAL § 5230-5230.2, available at <http://cms.hhs.gov/manuals/pub45pdf/smm5t.pdf>.

142. 42 U.S.C.A. § 1396a(a)(11)(B) (West Supp. 2001).

143. N.M. Stat. Ann. §§ 9-2A-4 (Michie 2002).

144. 42 U.S.C.A. § 1396a(19) (West Supp. 2001).

Thus, federal law requires that state agencies, including the agencies in charge of serving delinquent children, cooperate to provide necessary services to children and that cooperative arrangements simplify administration and serve the best interests of children.

C. Medicaid Managed Care Dramatically Reduces Access to Healthcare for Poor Children

The introduction of a managed care Medicaid system in New Mexico led to a crisis in mental health care and services for children in New Mexico. From its inception in 1965, until the early 1980s, Medicaid was administered on a fee-for-service basis across the nation. Treatment providers would provide medically necessary services and receive reimbursement from Medicaid based on an established fee schedule for the services. In the early 1980s, the Federal government began to permit states to request waivers of the fee-for-service structure.¹⁴⁵ Today, the federal government regularly awards waivers of the strict Medicaid fee-for service regulations, allowing states to contract with for-profit managed care companies.¹⁴⁶ These waivers are commonly referred to as 1915(b) waivers or "freedom of choice waivers."¹⁴⁷ The statutory provisions regarding the waivers make it clear that the transition to a managed care system cannot compromise the provision of services.

Medicaid waivers are permitted in order to promote cost-effectiveness and efficiency.¹⁴⁸ Under Federal law, the waiver may be granted only "if such restriction does not substantially impair access to such services of adequate quality where medically necessary."¹⁴⁹ The managed care organization must assure that it has adequate capacity and services to serve the expected enrollment.¹⁵⁰ The statutory scheme also includes specific provisions regarding managed care.¹⁵¹ It must assure that it offers an appropriate range of services and access to preventive and primary care services for the population expected to be enrolled in such services area, and that it maintains a sufficient number, mix, and geographic distribution of providers of services.¹⁵²

In practice, the implementation of managed care in New Mexico pursuant to a 1915(b) waiver compounded the difficulties with access to mental health and

145. 42 U.S.C.A. § 1396n(b) (West Supp. 2001).

146. See MARSHA REGENSTIEN & STEPHANIE E. ANTHONY, THE URBAN INSTITUTE, MEDICAID MANAGED CARE FOR PERSONS WITH DISABILITIES 3 (1998), available at <http://www.urban.org/UploadedPDP/occa11.pdf> (last visited June 17, 2003).

147. JANE PERKINS AND SARAH SOMERS, NATIONAL HEALTH LAW PROGRAM (NHELP), AN ADVOCATE'S GUIDE TO THE MEDICAID PROGRAM 2.6(1) (2001). The reference to "freedom of choice" waivers is ironic. One of the main impacts of these waivers is the elimination of recipients' free choice of providers.

148. 42 U.S.C.A. § 1396n(b) (West Supp. 2001).

149. 42 U.S.C.A. § 1396n(b)(1) (West Supp. 2001).

150. 42 U.S.C.A. § 1396u-2(b)(5) (West Supp. 2001).

151. 42 U.S.C.A. § 1396n(a)(2)(B).

152. *Id.*

behavioral health for children with special needs, including Jesse. The waiver program had a dramatic impact on behavioral health treatment in New Mexico and on Mr. Martinez's efforts to seek mental health services for Jesse. New Mexico operated its Medicaid program on a fee-for-service basis until 1997. Under the fee-for-service system, Medicaid recipients could take their Medicaid card to a health care provider and the provider would be reimbursed for their services.¹⁵³ In 1997, New Mexico obtained a waiver from the federal government to allow the state to begin replacing its fee-for-service Medicaid Program with a "managed care" program.¹⁵⁴ The program which led to a healthcare crisis for poor children in New Mexico, ironically called SALUD!, Spanish for HEALTH!, dramatically undermined the state's ability to comply with the five important mandates of the federal Medicaid law.

1. The Structure of and Implementation of Medicaid Managed Care Undermined the Amount, Duration and Scope of Medically Necessary Services

Under SALUD!, Medicaid recipients were required to enroll in a Managed Care Organization.¹⁵⁵ The Managed Care Organizations (MCOs) receive a flat fee, per beneficiary, per month, to pay for all Medicaid services provided.¹⁵⁶ The MCO pays for all services out of that flat monthly fee.¹⁵⁷

If the costs exceed the flat monthly fee paid to the Managed Care Organization, the costs must be paid by the MCO.¹⁵⁸ The MCO may profit if the costs are less than the monthly fee.¹⁵⁹ The structure of SALUD!, therefore, created an incentive to reduce the amount of services that are provided.¹⁶⁰ Other states have anticipated that the transition to a managed care system can cause difficulties for people with chronic mental health and medical needs.¹⁶¹ States have phased in managed care for Medicaid recipients with chronic health needs,¹⁶² and used transparent, comprehensive measures of risk assessment to set the appropriate rates, which include consideration of the health status of the insured.¹⁶³ Federal law even anticipates that children with disabilities receiving Supplemental

153. Taylor v. Otten, No. CIV. 98-1382 JC/DJS, Second Amended Complaint para. 49 (D. N.M. Apr. 19, 2000).

154. *Id.* at para. 50.

155. *See Report on Medicaid Managed Care in New Mexico*, Feb. 21, 2000, Expert Report prepared for Taylor v. Johnson, No. CIV. 98-1382 JC/DJS, at 6 (prepared by Henry T. Ireys, Ph.D., Associate Professor, School of Hygiene and Public Health, Johns Hopkins University).

156. *Id.*

157. *Id.*

158. *Id.*

159. *Id.*

160. *Id.*

161. *See id.* at 12 (Washington State implemented risk adjustment capitation rates based on a comprehensive study of a population with chronic physical and mental health conditions.).

162. *See id.* at 12.

163. *See id.* at 6-23.

Security Income will be exempt from managed care.¹⁶⁴ However, in New Mexico, children with special needs are required to participate in managed care, regardless of their health status.¹⁶⁵

The problems created by the incentive to provide fewer services were compounded by the fact that the Managed Care Organizations had to subcontract with behavioral health providers.¹⁶⁶ Three Behavioral Health Organizations (BHOs) were responsible for providing behavioral and mental health services for SALUD!.¹⁶⁷ Those BHOs, in turn, contracted with Regional Care Coordinators (RCCs) adding yet another level of administration to pay before the federal Medicaid dollars reached the actual behavioral health treatment providers.¹⁶⁸

The additional layer of administration not only complicated the system, but also added significantly to the costs of administration, compounding the significant reduction in Medicaid funding when managed care was implemented.¹⁶⁹ As a result, less Medicaid funding, and consequently fewer services, reach the individuals that truly need them.¹⁷⁰

The Human Services Department would have spent between \$68 million and \$73 million in the 1997-1998 fiscal year for Medicaid-funded behavioral health services under the fee-for-service system. Under managed care, the Human Services Department contracted to pay \$63 million. . . [h]owever, more than \$20 million of those dollars have gone to administrative costs and profit The [managed care system has] reduced actual spending for behavioral health services by over forty percent.¹⁷¹

A draft of a state funded study on the administrative costs involved in the audit of SALUD! reported that for every dollar spent on Medicaid in New Mexico, fifty-one cents was going toward administrative costs and profits for the managed care companies, compared to thirty-three cents per dollar under the fee-for-

164. See 42 U.S.C.A. § 1396u-2(a)(2)(A)(i) (West Supp. 2000).

165. See *Taylor v. Johnson*, No. CIV98-09776, Complaint for Declaratory and Injunctive Relief, para. 33 (2d Judicial D. Court, N.M., Oct. 8, 1998).

166. *Report on Medicaid Managed Care in New Mexico*, Feb. 21, 2000, Expert Report prepared for Taylor v. Johnson, No. CIV. 98-1382 JC/DJS, at 4 (prepared by Henry T. Ireys, Ph.D., Associate Professor, School of Hygiene and Public Health, Johns Hopkins University).

167. *Expert Report*, Feb. 21, 2000, prepared for Taylor v. Johnson, No. CIV. 98-1382 JC/DJS, at 25 (prepared by Neal Mazer, MD, MPH).

168. *Id.*

169. See *Report on Medicaid Managed Care in New Mexico*, Feb. 21, 2000, Expert Report prepared for Taylor v. Johnson, No. CIV. 98-1382 JC/DJS, at 2-3 (prepared by Henry T. Ireys, Ph.D., Associate Professor, School of Hygiene and Public Health, Johns Hopkins University) (citing *New Mexico SALUD! Medicaid Managed Care Program* (prepared by William M. Mercer, Inc., an actuarial firm hired by the State of New Mexico as a consultant)).

170. *Taylor v. Otten*, No. CIV. 98-1382 JC/DJS, Plaintiff's Second Amended Complaint para. 73 (D.N.M. Apr. 19, 2000).

171. See *id.*

service system.¹⁷² Advocates have asserted that the administrative costs were even higher under managed care than these figures indicate.¹⁷³

In addition, the complexity of the system has led to increased time and expense incurred by doctors trying to secure services for their patients.¹⁷⁴ The Medical Director of the University of New Mexico Children's Psychiatric Hospital testified before a legislative committee regarding SALUD!:

Administrative overhead has exploded. For example, we regularly interact with ten SALUD managed care entities Thus, for each child we must determine which pre-authorization processes, forms, phone numbers, formularies, clinical criteria, utilization review processes, documentation requirements, transportation rules, and provider manuals we must use. Our clinicians have less time for patient care Our faculty had less time, and fewer resources to train New Mexico's next generation of caregivers Recruitment and retention of qualified academic psychiatrists has become more difficult As currently implemented SALUD places [our program] at great risk.¹⁷⁵

Despite federal requirements that the "state provide such safeguards as may be necessary to assure that . . . such care and services will be provided, in a manner consistent with simplicity of administration and the best interest of the recipients,"¹⁷⁶ the system was too complex. Doctors and other participants in the system struggled with the technical challenges of dealing with several different companies. This led not only to an administrative nightmare, but also had an impact on substantive definitions and rights. Each Managed Care Organization had different procedures and different substantive definitions of core concepts, including the definition of medical necessity.

Federal law defines medically necessary services broadly to include payment for "services necessary for the maximum reduction of physical or mental disability and restoration of an individual to the best possible functional level" ¹⁷⁷ However, each managed care organization had its own definition. For example, one of the Managed Care Organizations had the following definition of medically necessary:

172. *SALUD!'s Delivery of Mental Health Services; Problems and Recommendations*, July 5, 2000: Hearing before the New Mexico Legislative Council Interim Health and Human Services Committee (testimony of Rafael M. Semansky, MPP, Judge David L. Bazelon Center for Mental Health Law).

173. Some advocates allege that the managed care organizations, behavioral care organizations and network managers collectively consumed more than thirty-six percent of all Medicaid Funds, more than nine times the administrative costs of the Medicaid program prior to managed care. See *Taylor v. Otten*, No. CIV 98-1383 JC/DJS Second Amended Complaint, para. 73 (filed D.N.M. Apr. 19, 2000).

174. See *Expert Report*, prepared for *Taylor v. Johnson*, No. CIV. 98-1382 JC/DJS, at 27 (prepared by Neal Mazer, MD, MPH) (Feb. 21, 2000).

175. *Mental Health Care Needs of New Mexico's Children*, October 5, 1999: Hearings before the New Mexico Legislative Health and Human Services Committee (testimony of Dr. Robert Bailey, Medical Director of the UNM Children's Psychiatric Hospital).

176. 42 U.S.C.A. § 1396a(19).

177. 42 U.S.C.A. § 1396d(a)13 (West Supp. 2001).

Section 1.6 "Medically Necessary"... shall mean (a) generally accepted by qualified professionals as necessary for the proper and efficient diagnosis and treatment of a Covered Person's mental health or substance abuse conditions, (b) not primarily for the convenience or preference of a Covered Person, the Covered Person's family or physician, clinician, or any other individual or institutional provider of Covered Services, (c) no more intrusive or restrictive than necessary to provide a proper balance of safety, effectiveness and efficiency, and (d) no more intense a level of service than can safely be provided.¹⁷⁸

This definition makes no mention of restoration of an individual to the maximum functional level. Rather, the definition appears to focus on efficiency, and specifically negates consideration of patient or family preference and convenience. The difference in funding and the difference in focus are reflected in the reduction in treatment beds and in the reduction of services.

A leading national legal advocacy group for people with mental disabilities, the Bazelon Center for Mental Health Law, analyzed the managed care system in New Mexico and found declining rates of community mental health authorizations under managed care,¹⁷⁹ as well as declining rates of inpatient psychiatric services without corresponding increases in community-based mental health services.¹⁸⁰ More "children with serious emotional disturbance are living in the community without support to enable them to function at home, school and work."¹⁸¹

The analysis revealed that behavioral health services were scarce for enrollees, that waiting times for services to be authorized violated SALUD!'s standards, that the percentage of SALUD!'s members receiving mental health services was low, and that there were "deplorably low" Medicaid case management services.¹⁸² The analysis also found that there were no intensive services available to children with serious emotional disturbance.¹⁸³ Mental services were of poor quality, with little follow up after inpatient hospitalization, and improper denials of care.¹⁸⁴

After three years of the SALUD! Program, the mental health services in New Mexico deteriorated to a point where the Albuquerque Journal ran a front page article entitled "Children in Crisis; Experts, Parents Grapple with Fewer Mental

178. Handout from Options, Behavioral Health Organization, to Training Attendees, Definitions-Medical Necessity (Fall 1997) (on file with the Georgetown Journal on Poverty Law & Policy).

179. *SALUD!'s Delivery of Mental Health Services: Problems and Recommendations*, Hearing before the New Mexico Legislative Council Interim Health and Human Services Committee, 8 (July 2, 2000) (testimony of Rafael M. Semansky, MPP, Judge David L. Bazelon Center for Mental Health Law).

180. *Id.* at 9.

181. *Id.*

182. *Id.* at 15-19.

183. *Id.* at 19

184. *Id.* at 19-20.

Health Services for Youth.”¹⁸⁵ The Medical Director of the Children's Psychiatric Hospital of the University of New Mexico reported that the mental health system in New Mexico “is not working.”¹⁸⁶ Of the eleven types of services, seven showed more than a 50% decrease since the start of the SALUD! Program.¹⁸⁷ No services reported an increase.¹⁸⁸ The number of residential treatment beds in the state plummeted from 1,100 to 600,¹⁸⁹ with seven residential treatment facilities, and two group homes closing down in the Albuquerque area alone.¹⁹⁰

Lengths of stay in treatment also decreased significantly.¹⁹¹ A reduction in length of stay leads to premature discharge of children with mental health needs, which in turn “leads to higher likelihood of treatment failure, increased recidivism (often to much higher levels of care), further destruction of the child's self esteem and confidence.”¹⁹² Even where longer periods were ultimately negotiated, the uncertainty regarding the lengths of stay that would be authorized compromised the ability to build the high quality relationships critical for the treatment of severely emotionally disabled children and youth with histories of abuse or multiple placements.¹⁹³

Managed care had a dramatic impact on the amount, duration and scope of treatment. The total number of Medicaid dollars was reduced. More Medicaid dollars were spent on additional layers of administrative bureaucracy. Service providers spent more time navigating the complex bureaucracy, leaving less time for direct patient care. Definitions of medical necessity were narrowed by the private MCOs. Lengths of stay were reduced, and many treatment centers and providers around the state closed their doors. The services that remained were compromised by uncertainty and diminished resources.

2. Early Periodic Screening Diagnosis and Treatment

The Early Periodic Screening Diagnosis and Treatment Program also suffered significantly when Medicaid Managed Care was implemented. The percentages of children being screened to identify medical conditions had been far below the federally required 80% participation rate prior to the implementation of managed

185. Jadrnak, *Children in Crisis: Experts, Parents Grapple with Fewer Mental Health Care Services for Youths*, ALBUQUERQUE JOURNAL, Sept. 5, 2000, at A1.

186. *Id.*

187. *Id.*

188. *Id.*

189. Taylor v. Johnson, No. CIV 98-1382, Corrected First Amended Complaint for Declaratory and Injunctive Relief (Class Action) (D.N.M. Apr. 19, 2000).

190. Memorandum on SALUD! Managed Care Concerns (Sept. 2000).

191. *Report Regarding Medicaid Managed Care in New Mexico*, Feb. 21, 2000, Expert Report prepared for Taylor v. Johnson, No. CIV. 98-1382 JC/DJS, at 25 (prepared by Marty Beyer, Ph.D.).

192. *Expert Report*, Feb. 21, 2000, prepared for Taylor v. Johnson, No. CIV. 98-1382 JC/DJS, 20 (prepared by Neal Mazer, MD, MPH).

193. *Id.* at 38.

care.¹⁹⁴ Unfortunately, even without managed care, few states met these goals.¹⁹⁵ New Mexico's participation rates prior to managed care were as follows:

EPSDT Screening rates for	1994	43%
	1995	35%
	1996	40%

When broken down into age categories, the percentages were even lower.

Age Categories 15-20 years old	1994	12%
	1995	10%
	1996	17% ¹⁹⁶

As the percentages reveal in 1995, even though the participation rates were set at 80%, only 10% of the children in Jesse's age group were participating in the EPSDT program.¹⁹⁷ These low numbers decreased further with the implementation of the managed care program in 1997, with less than 23% of all children enrolled in Medicaid Managed care receiving EPSDT screening in 1998.¹⁹⁸

3. Case Management

Case managers are essential to avoid treatment gaps, especially as services are reduced. The payment for case managers decreased 40% under managed care.¹⁹⁹ Case management companies went out of business, and parents reported an inability to find caseworkers for their children.²⁰⁰ As one expert explained, in a report on New Mexico's managed care system:

[a]lthough case management is an essential service for children with mental or behavioral disabilities, since the inception of Medicaid managed care the quantity and quality of case management services provided to that population is

194. See *Report on Medicaid Managed Care in New Mexico*, Feb. 21, 2000, Expert Report prepared for Taylor v. Johnson, No. CIV. 98-1382 JC/DJS, at 26 (prepared by Henry T. Ireys, Ph.D., Associate Professor, School of Hygiene and Public Health, Johns Hopkins University).

195. See *id.*

196. Taylor v. Otten, No. CIV. 98-1382 JC/DJS, Plaintiff's Second Amended Complaint, paras. 57, 58 (D.N.M. Apr. 19, 2000).

197. Moreover, even where a screen reveals a need for treatment beyond the age of nineteen, children who qualify for Medicaid under certain categories lose their Medicaid completely at nineteen. If a child loses Medicaid Coverage when he or she turns 19, then they lose their right to EPSDT services, even though the statute appears to require treatment until age 21.

198. Taylor v. Otten, No. CIV. 98-1382 JC/DJS, Plaintiff's Second Amended Complaint, paras. 61 (D.N.M. Apr. 19, 2000).

199. See Memorandum on SALUD! Managed Care Concerns (Sept. 2000).

200. Jadnak, *Children in Crisis*, *supra* note 185, at A1 (reporting that child with traumatic brain injury lost his case management when the company providing it went out of business; at that point the child had been through eight or nine case managers within a period of four years).

significantly reduced and is inadequate to provide continuity of care for children with disabilities and to enable them to access services²⁰¹

Or, as stated by the Deputy Director of Prevention and Intervention Division of New Mexico's Children, Youth and Families Department, "[i]n children's behavioral health, case management has virtually ceased to exist."²⁰²

4. Procedural Protections Were Evaded

The reduction in services under managed care was accompanied by a profound decrease in meaningful procedural protection from denials of service under the plan. Each MCO was required to establish an internal grievance procedure to permit challenges to denial of payment for medical assistance.²⁰³ The internal grievance procedures were flawed because it was difficult to discern how to access the grievance procedure, and because the MCO did not give written notice of proposed reductions in service.²⁰⁴

The authorization process for medical services became a negotiation between the providers and the MCOs regarding the extent of treatment that would be authorized. As one provider stated, "reports will show a zero or very low denial rate because providers accept the negotiated lower level of care."²⁰⁵ Parents see that their children are being denied services, but they have very few sources of information about the timing and basis for the denials of services, making it difficult, if not impossible to effectively appeal.

Another powerful barrier is the sheer lack of time and resources necessary to pursue a grievance in the SALUD system. The overwhelming paperwork and administrative bureaucracy associated with SALUD implementation . . . has made it impossible for many providers to pursue authorization for care that clinicians believe is clinically appropriate.²⁰⁶

201. *Report Regarding Medicaid Managed Care in New Mexico*, Feb. 21, 2000, Expert Report prepared for Taylor v. Johnson, No. CIV. 98-1382 JC/DJS, at 9 (prepared by Marty Beyer, Ph.D.).

202. *Report on Medicaid Managed Care in New Mexico*, Feb. 21, 2000, Expert Report prepared for Taylor v. Johnson, No. CIV. 98-1382 JC/DJS, at 38 (prepared by Henry T. Ireys, Ph.D., Associate Professor, School of Hygiene and Public Health, Johns Hopkins University) (citing Memorandum from Dr. Ken Martinez, Deputy Director of the Prevention and Intervention Division of New Mexico's Children, Youth and Families Department (Apr. 12, 1999)).

203. 42 U.S.C.A. § 1396u-2(b)(4) (West Supp. 2003).

204. *Expert Report*, Feb. 21, 2000, prepared for Taylor v. Johnson, No. CIV. 98-1382 JC/DJS, 30, 32 (prepared by Neal Mazer, MD, MPH).

205. *SALUD's Delivery of Mental Health Services; Problems and Recommendations*, July 5, 2000: Hearing before the New Mexico Legislative Council Interim Health and Human Services Committee (testimony of Rafael M. Semansky, MPP, Judge David L. Bazelon Center for Mental Health Law) (quoting letter from Joseph W. Avellar, Ph.D., Value Behavioral Health).

206. *Expert Report*, Feb. 21, 2000, prepared for Taylor v. Johnson, No. CIV. 98-1382 JC/DJS, at 30-31 (prepared by Neal Mazer, MD, MPH).

Another flaw in the grievance system is the potential for retribution against providers who file grievances against the MCOs. The provider must depend on the MCOs and BHOs for referrals, timely processing of requests, and payment. Concerns about retribution could impact a provider's willingness to file appeals, even if the provider had the necessary time and resources.²⁰⁷

5. Coordination of Efforts

Any coordination of efforts among other state agencies was difficult to discern. One expert reviewing New Mexico's managed care system commented, "it is unusual for children and their families to receive more than one service at a time, as the services available seem to be viewed as sequential steps rather than a comprehensive, multi-intervention treatment plan."²⁰⁸ The expert report goes on to explain that children with severe emotional and behavioral problems typically require "well-planned, timely and coordinated programming of multiple services simultaneously."²⁰⁹ However, the many levels of administration—from the Managed Care Organizations, to the Behavioral Health Organizations to the Regional Care Coordinator to the Provider or Provider Organization—created such complexity that meaningful coordination of efforts between the entities and other agencies was not practical.

Thus, the introduction of managed care undermined the amount, duration and scope of services, including EPSDT and case management services. Due process rights were undermined. The complexity of the system violated federal mandates requiring simplicity of administration and made cooperation among state agencies all the more difficult.

D. Systemic Efforts to Seek Compliance with the Medicaid Act, Including a Class Action Lawsuit

Advocates across the country have filed lawsuits seeking enforcement of federal statutory rights of Medicaid beneficiaries in managed care systems, including enforcement of all five of the mandates analyzed above.²¹⁰ Advocates have sued to challenge the lack of reasonably prompt services for children with severe behavioral, emotional or psychiatric disabilities, and the failure of a state

207. *Id.* at 32.

208. *Id.* at 19.

209. *Id.*

210. *Solter v. Health Partners of Phila.*, 215 F. Supp. 2d 533 (E.D. Pa. 2002) (addressing amount, duration and scope of medically necessary services); *Frew v. Gilbert*, 109 F. Supp. 2d 579 (E.D. Tex. 2000) (addressing EPSDT); *John B. v. Menke*, 176 F. Supp. 2d 786 (M.D. Tenn. 2001) (addressing case management); *Methodist Hosp. v. Ind. Family and Social Serv. Admin.*, 860 F. Supp. 1309 (N.D. Ind. 1994) (addressing procedural protections); *Taylor v. Otten*, No. CIV. 98-1382 JC/DJS, Plaintiff's Second Amended Complaint para. 45 (D.N.M. 2000) (coordination of efforts). Advocacy efforts, including litigation, are tracked by the National Health Law Program on their website, <http://www.nhelp.org>.

to assure an adequate network of mental health providers.²¹¹ The definition of medical necessity was clarified as the result of successful settlement negotiations in another case.²¹² Several lawsuits have been filed seeking compliance with EPSDT.²¹³ There has been litigation to prevent the termination of case management services for mentally ill recipients without due process,²¹⁴ and to enforce other procedural rights of Medicaid beneficiaries.²¹⁵ There is also pending litigation regarding coordination of efforts.²¹⁶

In New Mexico, advocacy efforts to prevent the denial of medically necessary services under managed care began long before SALUD! was implemented. Advocates for children with special needs attempted to be proactive once the New Mexico legislature authorized the Human Services Department to implement a managed care system for Medicaid recipients.²¹⁷ Advocates worked with the Human Services Department to develop a plan that would phase in people with special needs, after the plan had been implemented for healthy people.²¹⁸ The plan to phase in special needs children was abandoned by the Governor, Gary Johnson, in late 1996, and the state proceeded to include everyone in the capitated managed care system.²¹⁹

When SALUD! was about to be implemented, advocates for children with special needs filed a lawsuit seeking an injunction against the program seeking to exempt children with special needs from the managed care scheme.²²⁰ An agreement was reached based, in part, on promises that the MCOs would provide oral and written notices of grievance procedures, and also provide medical

211. *Kirk T. v. Houstoun*, No. 99-3253, 1999 U.S. Dist. LEXIS 15794 (E.D. Pa. 1999) (Defendant's Motion to Dismiss Denied).

212. *John B. v. Menke*, 176 F. Supp. 2d 786 (M.D. Tenn. 2001).

213. See Memorandum from Jane Perkins, Manju Kulkarni, and Lourdes Rivera, National Health Law Program, to Health Advocates re: Medicaid Managed Care Docket 3 (June 15, 2000), at <http://www.healthlaw.org/docs/MgdCareDocket.pdf>.

214. *Id.* (discussing *Eric H. v. Belshe*, No. 984402 (Sup. Ct. San Francisco, filed Jan. 31, 1997) ("petition for writ of mandamus filed on behalf of 12 young adults being terminated from mental health case management without due process notice and hearing")).

215. *Id.* (discussing *Metts v. Houstoun*, No. 97-CV-4123 (E.D. Pa. Mar. 27, 1998) (Settlement Agreement) ("settlement agreement strengthened numerous due process protections when managed care plans deny, reduce, or terminate outpatient services, including equipment and supplies, and prescription medications")).

216. *Id.* (discussing *Bates-Booker v. Houston*, No. 97-CV-3734 (E.D. Pa. Oct. 20, 1997) (Agreement) ("involved interplay between Medicaid and special education services")).

217. See Affidavit of Peter Cubra, June 5, 2003 (on file with author); see also Memorandum from Chuck Mulligan, New Mexico Human Services Department, to Persons Interested in Children's Behavioral Health (Nov. 14, 1997).

218. *Taylor v. Johnson*, No. CIV98-09776, Complaint for Declaratory and Injunctive Relief, para. 29 (2d Judicial D. Court, N.M., Oct. 8, 1998).

219. See N.M. ADMIN. CODE tit.8 ch.305 pt.5 (2003).

220. *Taylor v. Johnson*, No. CIV98-09776, Complaint for Declaratory and Injunctive Relief, para. 64 (D. N.M., Oct. 8, 1998) (referring to the filing of *V.C., et al v. HSD, et al*, No. CIV 97-7800 (2d Judicial D. Court, N.M. 1997)).

justification for transfers of children between facilities.²²¹ The Director of Human Services Department, Medical Assistance Division promised private meetings and public stakeholder meetings where providers, recipients and advocates could work with the state to identify and discuss potential systematic problems with the managed care program.²²²

The state did not keep those promises. Adequate notices were not provided.²²³ Children were transferred without notice from one residential treatment center to another.²²⁴ Meetings with the Medical Assistance Division Director were cancelled.²²⁵ Although the stakeholder meetings were initially well attended, it became clear that there was no follow up on either the requests or complaints that were made at those meetings, and the meetings eventually stopped.

In October 1998, a class action was filed in state court against the Governor of New Mexico, seeking, primarily, to enjoin the managed care system and seeking to reinstate the fee-for-service Medicaid program.²²⁶ Jesse joined the lawsuit through a next friend, an adult who could help make decisions regarding the lawsuit on his behalf.²²⁷ The complaint alleged systemic failure to comply with the Medicaid Act's requirement that the state provide medically necessary services and EPSDT to children with special needs.²²⁸ The complaint also alleged that the state failed to comply with the Americans with Disabilities Act²²⁹ and with several state statutes and regulations,²³⁰ including the Patient Protection

221. Letter from Charles Milligan, Director, Medical Assistance Division, New Mexico Human Services Department, to Peter Cubra 2-3 (Oct. 20, 1997).

222. *Id.* at 1.

223. Affidavit of Peter Cubra, June 5, 2003 (on file with author).

224. *Id.*

225. *See id.*

226. Taylor v. Johnson, No. CIV98-09776, Complaint for Declaratory and Injunctive Relief (2d Judicial D. Court, N. M. Oct. 8, 1998).

227. *See id.*; N.M. STAT. ANN., Rules of Civil Procedure for the District Courts, art. 4 Rule 1-017(c) NMRA (2002) (an incompetent person who does not have a duly appointed representative may sue through a next friend).

228. Taylor v. Johnson, No. CIV98-09776, Complaint for Declaratory and Injunctive Relief (2d Judicial D. Court, N. M. Oct. 8, 1998).

229. The Supreme Court has held that states are immune from suits by state employees for money damages under the Americans with Disabilities Act. *See University of Alabama v. Garrett*, 531 U.S. 356 (2000); *see generally Alden v. Maine*, 527 U.S. 706 (1999) (Congressional power under Article I of the United States Constitution does not include the power to subject nonconsenting states to private suits for damages in state courts). However, neither of these cases precluded actions for injunctive relief pursuant to the ADA, nor do they preclude suits against private companies or municipalities.

230. *See, e.g.*, N.M. ADMIN. CODE § 8.305.6.9(A) (2003) (MCOs must provide medically necessary services in a timely manner.), available at http://www.nmcpr.state.nm.us/nmac/_title08/T08C305.htm; *Id.* at § 8.305.6.9(B) (MCOs must contract with enough providers to deliver a level of care that is at least equal to community norms.); *Id.* at § 8.305.6.13(B) (MCOs must provide effective and efficient referrals.); *Id.* at § 8.305.6.13(A) (MCOs must provide sufficient network of providers with demonstrated expertise in treating seriously disabled mentally ill adults and seriously emotionally disturbed children.); *Id.* at § 8.305.8.12(F)(1)(a) (MCOs must actively work to improve the health status of its members with chronic conditions.); *Id.* at § 8.305.8.13 (MCOs must conduct appropriate utilization review.); *Id.* at § 8.305.9.11 (MCOs must coordinate with Medicaid Waiver programs.); *Id.* at § 8.305.9.12 (MCOs must

Act,²³¹ the Public Assistance Act,²³² and the Public Assistance Appeals Act.²³³ The defendants removed the federal claims court to federal court.²³⁴ The Second Amended Complaint was filed in April of 2000 in federal court. The author of this Article was named as Jesse Martinez's next friend.²³⁵

As the system got worse and the lawsuit progressed, a concerted effort was also made to persuade the federal Health Care Financing Administration (HCFA) to deny the approval for continuation of SALUD! for behavioral health under the § 1915 (b) waiver.²³⁶ In September 2001, HCFA officials came to New Mexico. They attended a community meeting in which providers came out in force to decry the condition of mental health services for children in the state. In October, a Congressional delegation, including Republican Representative Heather Wilson and Democratic Senator Jeff Bingaman from New Mexico, lobbied HCFA not to renew the waiver for the operation of managed care for mental health services.²³⁷ Senator Jeff Bingaman wrote to HCFA's acting administrator, stating:

The lack of access to services [is] causing devastating problems, not only for consumers and the behavioral health system, but also for the juvenile justice system, and thus, ultimately, for all the citizens of my state.²³⁸

The class action continued. It was contentious and heavily litigated. The state, which was represented by a private law firm, joined the Managed Care Organizations as parties to the state suit.²³⁹ Discovery was extensive, and a dozen separate Motions for Summary Judgment were filed by the defense.²⁴⁰ Private

comply with children's code to ensure adequate services for children in custody of the Children, Youth and Families Department.).

231. The New Mexico Patient Protection Act provides that managed health care plans "shall provide health care services that are reasonably accessible and available in a timely manner to each covered person." N.M. STAT. ANN. § 59A-57-4.B. (2)(1998). The Act further provides that managed care health plans must also provide reasonably accessible health care services that are available in a timely manner. "A health care plan shall ensure that . . . reasonable access is provided to out-of-network health care providers if medically necessary covered services are not reasonably available through participating health care providers . . ." N.M. STAT. ANN. § 59A-57 4.B.(3) (1998).

232. The Public Assistance Act, N.M. STAT. ANN. § 27-2-12.6B(1) (West 2000), provides that the managed care system must ensure "access to medically necessary services, particularly for [M]edicaid recipients with chronic health problems."

233. The New Mexico Public Assistance Appeals Act, N.M. STAT. ANN. § 27-3-3B (West 2002), provides recipients with a right to fair hearing.

234. Taylor v. Johnson, No. CIV98-1382 JC, Notice of Removal (D.N.M. Nov. 9, 1998).

235. Taylor v. Johnson, No. CIV98-1382 JC/DJS, Plaintiff's Second Amended Complaint (D.N.M. Apr. 19, 2000).

236. Affidavit of Peter Cubra, June 5, 2003, ¶ 8 (on file with author).

237. Jackie Jadrnak, *Mental Services Change Lauded: Feds Approve Move From Managed Care*, Albuquerque Journal, Oct. 20, 2000, at A1.

238. *Id.*

239. See Taylor v. Johnson, No. CIV 98-09776, Motion to Join Parties (D.N.M. Apr. 5, 1999).

240. Taylor v. Johnson, No. CIV 98-cv 01382, Docket Report (on file with the Georgetown Journal on Poverty Law & Policy).

efforts to settle the case were not successful.²⁴¹ The case was set for settlement facilitation.

During the settlement facilitation on October 19, 2000, with the trial date looming, all parties were seated at the table to see if the matter could be resolved prior to the trial. Dramatically, during the course of the discussion, the Governor's office recalled the representatives of the state and their counsel back to Santa Fe.²⁴² That day, the Health Care Financing Administration (HCFA) denied the approval of the waiver for behavioral health care in a letter approving a two-year continuation of waivers for physical health only.²⁴³ The state was required to return to a fee-for-service system for behavioral health care in ninety days, and to present a plan to HCFA to address the transition of special needs children under the plan.²⁴⁴ The federal action was welcome news to advocates for children with special behavioral health needs.²⁴⁵

The celebration was short-lived. Once Governor Bush became President Bush, the Governor of New Mexico indicated an intention to approach the President regarding the denial of the waiver. Despite a letter sent to the Secretary of Health and Human Services from the entire Congressional Delegation,²⁴⁶ and efforts by over forty behavioral health care providers and advocacy groups in New Mexico²⁴⁷ demonstrating concern about the adverse consequences of allowing waivers for behavioral health, HCFA decided to reverse its decision, permitting the continuation of a modified managed care system.²⁴⁸

The approval required the state of New Mexico to comply with twenty-four conditions, including improvements in review of service authorization decisions, communication with beneficiaries and increases in network capacity.²⁴⁹ However the managed care system covering all beneficiaries for a fixed, per-person cost was reauthorized.²⁵⁰

On paper, the conditions set forth in the HCFA letter included many of the changes sought by the lawsuit.²⁵¹ Moreover, the conditions were significant

241. Affidavit of Peter Cubra ¶ 10 (June 5, 2003) (on file with author).

242. *Id.* ¶ 13.

243. Letter from Tim Westmoreland, Director, Department of Health and Human Services, Health Care Financing Administration, to Robert T. Maruca, Director, New Mexico Human Services Department, Medical Assistance Division (Oct. 19, 2000).

244. *Id.*

245. Jadrnak, *Mental Services Change Lauded*, *supra* note 237, at A1.

246. Letter from Senator Pete Domenici, Congresswoman Heather Wilson, Senator Jeff Bingaman, Congressman Tom Udall and Congressman Joe Skeen to Tommy Thompson, Secretary of the U.S. Department of Health and Human Services (Feb. 14, 2001).

247. Letter from New Mexico Children's Advocacy Agencies to Penny Thompson, Acting Director, Center for Medicaid and State Operations (Jan. 26, 2001).

248. Letter from Mike Fiore, Director, Health Care Financing Administration, Center for Medicaid and State Operations, Family and Children's Health Programs Group, to Robert T. Maruca, Director New Mexico Human Services Department, Medical Assistance Division (Feb. 16, 2001).

249. *See id.*

250. *Id.*

251. *See id.*

enough that it became difficult to maintain the class action suit.²⁵² The expert reports had been on the prior system.²⁵³ All of the evidence collected during discovery related to the managed care system that was in effect prior to the HCFA letter. Many of the claims set forth in the class action became somewhat moot. The lawyers for the children had spent hundreds of thousands of dollars worth of time on the lawsuit,²⁵⁴ and were threatened with losing all of their attorney fees under new case law.²⁵⁵ Despite the continuing crisis in behavioral health for children, it did not seem possible to resolve it through continued litigation of the class action. The lawsuit settled with little more than the state promising to comply with the HCFA mandates, and to work with a Medicaid Advisory group to develop a more responsive system. By re-approving the waiver, despite the known crisis it created for New Mexico's children, HCFA became another agency evading responsibility for the care of poor children in this nation.

E. Failure to Provide Medically Necessary Services to Jesse

Jesse showed clear signs of severe mental illness and moderate mental retardation as a teenager. Mr. Martinez continued his struggle to secure services for Jesse through those early teen years, during the implementation of managed care, and throughout the pendency of the class action lawsuit seeking services for Jesse and other children like him.

1. Jesse's Struggle with Mental Illness and Mental Disability During His Early Teen Years

Jesse attempted to commit suicide for the first time when he was fourteen years old. He was hospitalized for one week and released. His mental health did not improve, and Mr. Martinez was extremely concerned. He worried that his son would end up incarcerated in the juvenile justice system. As Jesse approached fifteen years of age, Mr. Martinez went to his own doctor to seek assistance in hospitalizing Jesse. Pursuant to the doctor's report that Jesse was a danger to himself and others, Jesse was civilly committed for seventy-two hours in January 1996. The doctors told Mr. Martinez that Jesse was "anti-social" and that there was nothing really wrong with him. They reached this conclusion despite the fact that they witnessed Jesse call friends and tell them to go blow up his father's house because his father was trying to have him committed. Jesse was released back to his home without follow-up services.

The Martinez family lives in San Jose, an old New Mexico family neighborhood in the home that belonged to Mr. Martinez's great-grandfather. Some of the

252. Affidavit of Peter Cubra ¶ 14 (June 5, 2003) (on file with author).

253. *Id.* ¶ 15.

254. *Id.* ¶ 16.

255. *Buckhanon v. W. Va. Dept. of Health and Human Res.*, 532 U.S. 598 (2001).

families in the neighborhood have been dealing drugs for generations.²⁵⁶ Mr. Martinez was vigilant in trying to keep his sons from hanging out on the streets of the neighborhood because of his concerns about the prevalence of drugs. However, a counselor at Jesse's middle school convinced Mr. Martinez to let Jesse go outside and befriend the other neighborhood kids. The counselor told Mr. Martinez that Jesse needed to learn how to socialize. The first family with whom Jesse started to spend time included grandparents who dealt heroin. Their home was the place where Jesse eventually died.

A treatment provider explained the impact that the neighborhood and gangs had upon Jesse, given his mental state: "His need for affiliation and acceptance, led him to gang life where he could continue to act out his anger in an environment that accepted and encouraged that type of behavior." It was through this association that he became acquainted with drugs, alcohol and illegal activities. It is very likely that he was using the drugs as a way of "self-medicating."²⁵⁷ "Jesse's immaturity and low intelligence has led him into easily being used by other gang members. Because of this, he has frequently placed himself in high-risk situations."²⁵⁸

By the time Jesse was fifteen years old, his life had been profoundly shaken by violence. One of Jesse's closest friends, Max, who was significantly older than Jesse and was very protective of him, was sent to prison where he was stabbed to death. Jesse watched as two of his friends were shot at close range right in front of him. Jesse was also severely beaten with a baseball bat by rival gang members. He took several blows to the head during the beating.

Jesse was not sleeping at night. He stayed up to compulsively wash his clothes. He began to hear voices in his head.²⁵⁹ In June of 1996, Jesse tried to kill himself again²⁶⁰ and was hospitalized. Mr. Martinez requested extensive and long-term mental health services for Jesse. Jesse was hospitalized for only one week and then released back to the neighborhood with no follow-up services.

Jesse had been placed on probation by the juvenile court²⁶¹ and was taken to the juvenile detention center, commonly known as the D-Home, for an alleged violation of his probation. After appearing before the judge and finding out that he could not go home, Jesse tried to hang himself with a bed-sheet in the detention center. He was returned to the hospital. A nurse told Mr. Martinez that she was sorry that they had previously discharged Jesse because Jesse really

256. See Jeff Jones, *Grandma Held in Heroin Case*, ALBUQUERQUE JOURNAL, July 14, 2000, at A1.

257. NEW MEXICO DEPARTMENT OF HEALTH, SEQUOYAH ADOLESCENT TREATMENT CENTER, INTEGRATED SUMMARY 3 (July 30, 1997).

258. NEW MEXICO DEPARTMENT OF HEALTH, SEQUOYAH ADOLESCENT TREATMENT CENTER, PANEL REVIEW (Oct. 28, 1997).

259. UNIVERSITY OF NEW MEXICO, HEALTH SCIENCES CENTER, PSYCHOLOGICAL EVALUATION REPORT 3 (May 14, 1997).

260. UNIVERSITY OF NEW MEXICO, HEALTH SCIENCES CENTER, SCHOOL OF MEDICINE, NEUROPSYCHOLOGICAL SCREENING EVALUATION 3 (Aug. 12, 1996).

261. Jesse's Experience in the Juvenile Justice system is documented, *infra* Section IV.

needed help. When Mr. Martinez asked the nurse why they had not kept him, the nurse said that the staff had to be more selective in anticipation of the upcoming change in Medicaid from fee-for-service to managed care.

When Jesse was sixteen, an evaluator reported on the seriousness of Jesse's problems:

"[Jesse is] ill-equipped to deal with the disadvantages life has dealt him—in the form of ongoing family problems, ongoing negative neighborhood influences, language and learning disabilities, academic problems. Thus, his learning problems and his disorder(s) of thought and mood have contributed to his substance abuse/dependence, to a serious pattern of self-destructive behavior, and the development of a concurrent conduct disorder with a substantial aggressive component."²⁶²

The evaluator also noted, however, that there "was a child-like quality" to Jesse's presentation.²⁶³

Jesse showed some of his charming, innocent qualities during evaluations. In one, he said, "I bet schizophrenic people give really crazy answers to these."²⁶⁴ Jesse also described his feelings for his mother, stating that he was "mad at her for abandoning us, but I still don't like it when people talk trash about her."²⁶⁵ Jesse also revealed his concerns about himself: "I move around too much. That's what I hate about myself. I can't sit still at all."²⁶⁶ Jesse was diagnosed with "Mood Disorder, with symptoms suggestive of Generalized Anxiety Disorder."²⁶⁷ Jesse said that he was thinking about his deceased friends. He told the evaluator, "maybe I should just die and be with my home boys." He also commented, "I just need to get my life together and stop getting in trouble."²⁶⁸

Two weeks after his admission to the hospital for his second suicide attempt, Jesse was transported to back to the D-Home,²⁶⁹ and released on house arrest. A

262. UNIVERSITY OF NEW MEXICO, HEALTH SCIENCES CENTER, PSYCHOLOGICAL EVALUATION REPORT 8 (May 14, 1997).

263. UNIVERSITY OF NEW MEXICO, HEALTH SCIENCES CENTER, PSYCHOLOGICAL EVALUATION REPORT 5 (May 14, 1997).

264. UNIVERSITY OF NEW MEXICO, HEALTH SCIENCES CENTER, SCHOOL OF MEDICINE, NEUROPSYCHOLOGICAL SCREENING EVALUATION 2 (Aug. 12, 1996).

265. *Id.*

266. *Id.*

267. *Id.*

268. *Id.* Jesse said several times during his life that he would like to tell his story. Unfortunately, he was killed before he was able to tell it. There are only a few direct quotes from Jesse in this Article. This quote from Jesse demonstrates the power of Jesse's own words to provide insight into his character and mental state. See DOUGLAS BIKLEN AND PHILIP SCHEIN, PUBLIC AND PROFESSIONAL CONSTRUCTIONS OF MENTAL RETARDATION: GLEN RIDGE AND THE MISSING NARRATIVE OF DISABILITY RIGHTS, Vol. 39, No. 6:436-451 (Dec. 2001) (exploring the implications of others speaking about persons labeled as having mental retardation).

269. See UNIVERSITY OF NEW MEXICO, HEALTH SCIENCES CENTER, SCHOOL OF MEDICINE, NEUROPSYCHOLOGICAL SCREENING EVALUATION 3 (Aug. 12, 1996).

few months later, after some very difficult times, including an incident of police brutality that is described below, Jesse was back in the detention center, on suicide watch. This time, he was released from the detention center to a psychiatric hospital where he was diagnosed as having an episode of severe major depression, and later "as having a psychotic mental disorder of some kind, possibly schizophrenia."²⁷⁰

The hospital perceived Jesse to be less mature than his peers, and implemented a simpler behavioral program that was "more oriented towards positive consequences."²⁷¹ The therapists described Jesse as responding positively to that program.²⁷² After five months in treatment, Jesse appeared cooperative and calm to a forensic evaluator who suggested that Jesse's medication was effectively controlling his anxiety and mood. Jesse still reported hearing voices but said that they were "not bothering him as much."²⁷³

Jesse's testing showed an "emotionally immature boy who, at best, has limited coping mechanisms. This leaves him chronically vulnerable to easy 'overload' by internal and external stresses, to confused and painful feelings, faulty judgment, poor control of his emotions and behavior, and impulsivity."²⁷⁴ Jesse showed short-term memory problems, and he performed at a rate equivalent to that of a seven and a half-year-old on at least one of the tests.²⁷⁵ The tests also showed significant neuropsychological impairments that significantly affect cognitive and emotional functioning.²⁷⁶ His diagnosis included depression with psychotic features or Schizoaffective Disorder, Schizophrenia, Bipolar Disorder, a Moderate Conduct Disorder, Polysubstance Dependence and a history of closed head injury.²⁷⁷

Jesse was also found to have mental retardation. While Jesse had shown an IQ of 90²⁷⁸ and 81²⁷⁹ on previous IQ tests, the test administered in December 1996 showed a Verbal IQ of 67, a Performance IQ of 75, with a Full scale IQ of 69.²⁸⁰ An IQ of 69 indicates that Jesse fell within the Borderline to Mentally Retarded

270. UNIVERSITY OF NEW MEXICO MENTAL HEALTH SCIENCES CENTER, PSYCHOLOGICAL EVALUATION REPORT 4 (May 14, 1997).

271. *Id.*

272. *Id.*

273. *Id.* at 5.

274. *Id.* at 9.

275. MEMORIAL HOSPITAL, NEUROPSYCHOLOGICAL EVALUATION 3 (May 30, 1997).

276. *Id.* at 4.

277. NEW MEXICO DEPARTMENT OF HEALTH, SEQUOYAH ADOLESCENT TREATMENT CENTER, INTEGRATED SUMMARY (July 30, 1997).

278. ALBUQUERQUE PUBLIC SCHOOLS, CONFIDENTIAL DIAGNOSTIC REPORT 6 (Sept. 24, 2000).

279. ALBUQUERQUE PUBLIC SCHOOLS, SPECIAL EDUCATION DEPARTMENT, MULTIDISCIPLINARY EVALUATION REPORT 3 (Apr. 12, 1994).

280. MEMORIAL HOSPITAL, NEUROPSYCHOLOGICAL EVALUATION 2 (May 30, 1997) (The evaluator stated, "the best estimate of for his true functioning would probably be his performance IQ Score of 75. Thus it is predicted that his intellectual functioning falls within the borderline range.").

range.²⁸¹ The differences in IQ have been attributed to variations on Jesse's effort and, alternatively, to a "blow to the head,"²⁸² which could have been caused by the beatings he took from gang members or the police.

Despite this litany of findings and diagnoses, Jesse was removed from the psychiatric hospital and placed back in the juvenile detention center due to the escalation of aggressive behaviors. "Because he was currently on probation . . . they were able to violate his probation and place him in detention."²⁸³

2. Jesse's Experience During the Implementation of Medicaid Managed Care

The impact that Medicaid Managed Care would have on Jesse's access to treatment became clearer as the implementation approached in the summer of 1997. Jesse was placed at a highly structured residential treatment center for violent adolescents, Sequoyah Adolescent Treatment Center, in July of 1997. The treatment records state:

[b]ecause Jesse's case appears to be somewhat complicated, it is difficult to determine length of treatment at this time. Also, the new Medicaid Managed Care System will certainly influence his length of stay after August 31. He will likely stay at Sequoyah at least three months with very tight wrap-around services following discharge. Due to the family history of mental illness, it is possible that Jesse will require long-term mental health treatment of several years to come.²⁸⁴

The medical reports during those months also state that Jesse's prognosis was "guarded,"²⁸⁵ and that "wrap-around services will need to be very comprehensive and appropriate for this family."²⁸⁶

281. AMERICAN ASSOCIATION ON MENTAL RETARDATION, *MENTAL RETARDATION: DEFINITION, CLASSIFICATION, AND SYSTEMS OF SUPPORTS* (9th ed. 1992).

282. NEW MEXICO DEPARTMENT OF HEALTH, SEQUOYAH ADOLESCENT TREATMENT CENTER, INTEGRATED SUMMARY 1 (July 30, 1997). It is also possible that the scores were inflated so that Jesse would be eligible for the Sequoyah Adolescent Treatment Center, which does not accept children with mental retardation. Mr. Martinez was later informed by a staff member at Sequoyah that his son had mental retardation, but that Jesse would not have been admitted for treatment into the program if his IQ scores had been any lower.

283. NEW MEXICO DEPARTMENT OF HEALTH, SEQUOYAH ADOLESCENT TREATMENT CENTER, DISCHARGE SUMMARY 1 (Dec. 30, 1997) (on file with the Georgetown Journal on Poverty Law & Policy).

284. NEW MEXICO DEPARTMENT OF HEALTH, SEQUOYAH ADOLESCENT TREATMENT CENTER, INTEGRATED SUMMARY 2 (July 30, 1997) (on file with the Georgetown Journal on Poverty Law & Policy).

285. NEW MEXICO DEPARTMENT OF HEALTH, SEQUOYAH ADOLESCENT TREATMENT CENTER, PANEL REVIEW (Sept. 27, 1997); NEW MEXICO DEPARTMENT OF HEALTH, SEQUOYAH ADOLESCENT TREATMENT CENTER, PANEL REVIEW 2-3 (Oct. 28, 1997) (on file with the Georgetown Journal on Poverty Law & Policy).

286. NEW MEXICO DEPARTMENT OF HEALTH, SEQUOYAH ADOLESCENT TREATMENT CENTER, PANEL REVIEW (Sept. 27, 1997); NEW MEXICO DEPARTMENT OF HEALTH, SEQUOYAH ADOLESCENT TREATMENT CENTER, PANEL REVIEW 2-3 (Oct. 28, 1997) (on file with the Georgetown Journal on Poverty Law & Policy).

The mental health problems were compounded by serious physical illness. In September 1997, Jesse reported severe pain in his abdomen. His complaints were not taken seriously until he became extremely ill and had to be hospitalized on an emergency basis for appendicitis.²⁸⁷ Following the surgery Jesse was still very sick for weeks, and could not really benefit from the treatment program.

Mr. Martinez expressed concern that Jesse would be released from the treatment center prematurely. He was specifically concerned about any reduction in the level of care. Nonetheless, Jesse was discharged on December 30, 1997. The discharge plan stated that Jesse would go to day treatment, and that he would have a Behavioral Health Management Specialist in the home, as well as individual and family therapy, medication management and monitoring by his Juvenile Probation officer from Children, Youth and Families.²⁸⁸ No therapy or Behavioral Management Specialist was ever provided. The school was inappropriate and frustrating for Jesse because he could not read, write or do math. The juvenile probation officer threatened to violate Jesse's probation for failing to attend school.

Within a month and a half, Jesse was brought to an in-patient treatment at a different center. He was seventeen years old. Developmentally he was around eight years old.²⁸⁹ Jesse suffered from a lack of self-esteem. He "always tries to make others laugh or gets angry if he doesn't get enough attention."²⁹⁰ A few weeks after his admission at the new facility, the staff recommended that Jesse be discharged to a group home, or to live with his "auntie" in Oregon. Mr. Martinez opposed these recommendations²⁹¹ because he did not feel that either a group home or his sister's home would provide enough treatment or structure for his son Jesse.²⁹²

The psychiatrist ordered Jesse's discharge on April 15, 1998. Mr. Martinez fought to have Jesse remain in treatment. When he came to pick Jesse up, he pleaded with the nurse for treatment for Jesse. The nurse told the doctor that Jesse

287. Several medical personnel told Mr. Martinez that he could have sued for malpractice for failure to attend to Jesse's medical condition. Mr. Martinez chose not to do so out of fear of retaliation against his children, and out of respect for Dr. Gardner, the Director of the facility.

288. NEW MEXICO DEPARTMENT OF HEALTH, SEQUOYAH ADOLESCENT TREATMENT CENTER, DISCHARGE SUMMARY 3 (Dec. 30, 1997) (on file with the Georgetown Journal on Poverty Law & Policy).

289. DESERT HILLS CENTER FOR YOUTH AND FAMILIES, PROGRESS NOTES, Mar. 19, 1998 (Apr. 2, 1998) (on file with the Georgetown Journal on Poverty Law & Policy).

290. *Id.* at Apr. 2, 1998.

291. *Id.* at Mar. 23, Apr. 2 and Apr. 23, 1998.

292. Jesse also applied for services under the "DD waiver" program, a state program, exempt from specific federal restrictions, making Medicaid funding available for group homes and other services for persons with developmental disabilities. See Developmental Disabilities Act N.M. STAT. ANN. § 28-16A-1 (West 2002). Unfortunately, Jesse's application for the program was denied, and even if granted, there was, and still is, a seven to eight year waiting list for services under the New Mexico "DD waiver" program. See *Lewis v. N.M. Dep't of Health*, No. CIV 99-0021MV1 LCS, Amended Complaint for Violations of Civil Rights and Injunctive Relief (D.N.M. 1999).

needed help, and should not be discharged. The facility kept him for another few days before discharging him to the streets without services.

Two days after the discharge, on April 22, 1998, Jesse's behavior was out of control and Mr. Martinez had to call the police. The police took Jesse to the hospital,²⁹³ and he was returned to the treatment facility. He had not taken his prescribed medications and had been smoking crack.²⁹⁴ As soon as Jesse was returned to the facility, there was a clear threat that he would be returned to the juvenile justice system. The receiving note at the facility said that part of Jesse's "Treatment Plan" was to notify the Juvenile Probation officer to proceed with a court-ordered group home.²⁹⁵ Again, the treatment facility used the threat of the juvenile justice system and the court-ordered group home as part of its "treatment plan," despite its contention that "Jesse appear[ed] to function at an eight year old level and d[id] not understand the consequences of his behavior."²⁹⁶ Mr. Martinez was not convinced that the placement was appropriate, but he wanted his son to get treatment rather than be incarcerated or released with inadequate treatment.

While in treatment, Jesse had become angry and verbally abusive with the staff because they would not let him go see his brother who was in a different unit at the treatment center.²⁹⁷ The police were not willing to take Jesse to the detention center.²⁹⁸ The staff pressed Jesse's admission to a group home.

Mr. Martinez insisted that a group home would not have sufficient services to address Jesse's mental health needs; he agreed to meet with the Medicaid Manager for Community Residential Programs as arranged by Jesse's care coordinator at the managed care company.²⁹⁹ After the meeting, the Manager of Community Residential Programs stated that Jesse needed more extensive treatment than a group home could provide. In his opinion, Jesse needed treatment in a facility that could address both the mental health and substance abuse issues.³⁰⁰ "Having a serious mental illness such as schizophrenia and a serious substance abuse problem are interrelated issues and should be addressed simultaneously. Treatment for the 'dually diagnosed' in general requires longer term, more intensive treatment."³⁰¹

At that point, Mr. Martinez could clearly see his son's precarious future. On

293. STATE OF NEW MEXICO, UNIFORM INCIDENT REPORT (Apr. 22, 1998) (on file with the Georgetown Journal on Poverty Law & Policy).

294. DESERT HILLS CENTER FOR YOUTH AND FAMILIES, PSYCHIATRY RECEIVING NOTE (Apr. 22, 1998) (on file with the Georgetown Journal on Poverty Law & Policy).

295. *Id.*

296. DESERT HILLS CENTER FOR YOUTH AND FAMILIES, PROGRESS NOTES, *supra* note 289, at Apr. 23, 1998.

297. *Id.*

298. *Id.* at Apr. 27, 1998.

299. Thus, there was some level of coordination between the Medicaid provider and Children Youth and Families Division, where the agency would have reduced its costs by transferring Jesse to a lower level of treatment.

300. CHILDREN, YOUTH AND FAMILIES DEPARTMENT, RECOMMENDATION LETTER (Apr. 30, 1998).

301. *Id.*

April 30, 1998, Mr. Martinez went with his daughters to the family's managed care provider to try to secure services for Jesse. The family explained to the care coordinator that Jesse needed more treatment for chemical dependency, and was feeling like a failure and like "a piece of trash" because he keeps getting bounced around from program to program. Mr. Martinez told the representative in charge of securing appropriate services for his son, "[t]he longer we wait, the worse he may get."³⁰²

Despite these efforts and pleas for help, the very next day, on May 1, 1998, Jesse was taken to the D-home.³⁰³ The discharge summary, while indicating that Jesse has severe limitations due to organic brain damage, stated that Jesse was "recalcitrant to all treatment."³⁰⁴ "It was decided that he would be sent to the D-Home because of the violation of his probation with drug abuse."³⁰⁵

"It was our belief that he . . . will be unamenable to any true psychotherapeutic attempts at this point in life and basically needs to be involved in the penal system to have any effect whatsoever."³⁰⁶ When Mr. Martinez filed a formal complaint to challenge the reduction in services, it was discharged because the action was not considered a reduction in services.³⁰⁷

3. Jesse's Struggle During the Pendency of the Class Action Seeking Access to Mental Health Services

During the course of the class action litigation, in January 1999, just after Jesse turned eighteen, the doctors were going to discharge Jesse from residential treatment where he had been placed, even though the treating doctor stated that the discharge would be "bad for Jesse."³⁰⁸ Jesse's next friend made efforts to discern the reasons for Jesse's imminent discharge, and to see if a more realistic discharge plan could be developed. However, Jesse was discharged on February 16, 1999.³⁰⁹ Although the treatment providers stated that the "team" had been

302. Notes of Meeting with Patrick Martinez and family, Conference Room, OPTIONS, Albuquerque, New Mexico (Apr. 30, 1998).

303. DESERT HILLS CENTER FOR YOUTH AND FAMILIES, DISCHARGE SUMMARY 1-2 (May 31, 1998) (on file with the Georgetown Journal on Poverty Law & Policy).

304. *Id.*

305. *Id.*

306. *Id.* at 2.

307. Hearing Decision and Plaintiff's Record on Appeal at P1.2348 (Aug. 12, 1998); see Patrick Martinez v. William Johnson, Appeal from the New Mexico Human Services Department, NEW MEXICO HUMAN SERVICES DEPARTMENT, ADMINISTRATIVE HEARINGS BUREAU, NOTICE OF DISMISSAL OF CASE NO. 98-MC-007 (July 31, 1998).

308. Memorandum of Telephone Conversation between Practicing Law Student, The University of New Mexico School of Law, and Dr. Tolkusta, Treating Physician (Feb. 8, 1999) (on file with the Georgetown Journal on Poverty Law & Policy).

309. NEW MEXICO DEPARTMENT OF HEALTH, SEQUOYAH ADOLESCENT TREATMENT CENTER, WEEKLY CALENDAR OF ACTIVITIES (Feb. 16, 1999) (on file with Georgetown Journal of Poverty Law & Policy).

working on the discharge plan for months,³¹⁰ Mr. Martinez was not aware of the discharge plan. Jesse's discharge plan indicated that he was to attend one session of Anger Management and one Individual Therapy Session each week. He was also assigned to attend Reading, Math, and Basic Skills Classes at TVI, a local community college.³¹¹

Within days of his discharge, Jesse was getting restless, and Mr. Martinez was concerned about the level of Jesse's interaction with others.³¹² Within four months, Jesse had allegedly failed four drug tests and was back in the D-Home for violating his probation.³¹³ Jesse still needed mental health services, but it did not appear that any treatment was forthcoming. A couple of weeks later, due to the persistence of a law student assisting Jesse's next friend, an assessor from another treatment program came to visit Jesse in the D-Home, and found that Jesse met the criteria for Residential Treatment which would address "anger management" and "drug and alcohol issues."³¹⁴ She also found him to be a suicide risk.³¹⁵

Despite the repeated medical indications that Jesse would need extensive, long-term treatment, the initial utilization review approval for placement at a Residential Treatment Center was for only fifteen days.³¹⁶ Despite Jesse's clear cognitive limitations, he was required to sign a behavior "contract" in order for the placement to be approved.³¹⁷

Mr. Martinez, and the social worker at the Public Defender Department, worked diligently to secure neuropsychological testing and to lay the groundwork for an adequate discharge plan. However, without any prior notice, other than general discussions about Jesse's eventual discharge, the staff at the center called Mr. Martinez on July 28, 1999 and told him to pick Jesse up. Mr. Martinez was enraged by the premature discharge. When he expressed concern and surprise about the imminent release, Mr. Martinez was told that it would be in Jesse's best interest to be picked up as soon as possible, because it is common for

310. Memorandum of Telephone Conversation between Practicing Law Student, The University of New Mexico School of Law, and Dr. Tolkusta, Treating Physician (Feb. 8, 1999).

311. NEW MEXICO DEPARTMENT OF HEALTH, SEQUOYAH ADOLESCENT TREATMENT CENTER, WEEKLY CALENDAR OF ACTIVITIES FOR JESSE MARTINEZ (Feb. 16, 1999) (on file with the Georgetown Journal on Poverty Law & Policy).

312. Memorandum of Telephone Conversation with Patrick Martinez, Father of Jesse Martinez (Feb. 25, 1999) (on file with the Georgetown Journal on Poverty Law & Policy).

313. Case Transfer Memorandum From Practicing Law Student, The University Of New Mexico School Of Law, To April Land, Next Friend To Jesse Martinez (May 25, 1999).

314. Letter from Laura G. Clark, Intake Specialist, Hogares, Inc., to Practicing Law Student, The University of New Mexico School of Law (May 11, 1999) (on file with the Georgetown Journal on Poverty Law & Policy).

315. *Id.*

316. *See* HOGARES, INC., ALBUQUERQUE, NEW MEXICO, UTILIZATION REVIEW REPORTING FORM FOR JESSE MARTINEZ (May 18, 1999) (on file with the Georgetown Journal on Poverty Law & Policy).

317. *Id.*

kids to get very anxious when they know that they are going to be discharged.³¹⁸

When questioned about the sudden and premature release of Jesse to his father's home, the case manager at the program said that transitional services were not available at the treatment facility, and that independent living programs were not restrictive enough for Jesse.³¹⁹ He was, therefore discharged to an even less restrictive placement: the family home. He was supposed to live at home and attend a day facility, even though home was not an "appropriate place for him," in the long term.³²⁰ According to the case manager at the residential treatment center, the staff at the day treatment center was responsible for locating a permanent placement. However, the staff at the day treatment center was not even aware that Jesse had been discharged from residential treatment.³²¹

Jesse was not able to comply with his outpatient treatment and a warrant was issued for his arrest.³²² He then ran away from home because he feared arrest. Jesse showed up a few days later and was returned to the D-Home. Jesse's treating psychiatrist, who prescribed medications for him, wrote a letter on September 1, 1999 stating, "I strongly believe that incarceration will not only worsen his current mental state, it would prevent Jesse access to mental health care" An alternative placement, other than his home, was the critical issue.³²³ Nonetheless, Jesse remained in juvenile detention.

The search for a placement for Jesse intensified as his mental health deteriorated in the detention center. Jesse's next friend contacted a treatment center in northern New Mexico, suggested by the social worker at the public defender's office. The intake worker explained that the treatment center was "at the mercy of [the BHOs (Behavioral Health Organizations)]."³²⁴ The worker explained that, "managed care is taking its toll on clinicians. People are fed up. Ninety percent of staff time is spent on managed care."³²⁵ She stated that they would consider taking Jesse, but would need more information.³²⁶

The managed care organization had contracted with a consortium of providers (the "Consortium") to do case management and prior authorizations for inpatient

318. Memorandum of Telephone Conversation with Patrick Martinez, Father of Jesse Martinez (Aug. 11, 1999) (on file with the Georgetown Journal on Poverty Law & Policy).

319. Memorandum of Telephone Conversation with Hogares, Inc., Caseworker (Aug. 10, 1999) (on file with the Georgetown Journal on Poverty Law & Policy).

320. *Id.*

321. Memorandum of telephone conversation with RHOC Caseworker (Aug. 10, 1999) (on file with the Georgetown Journal on Poverty Law & Policy).

322. In the Matter of Jesse Martinez, CHCH 96-0285/95-2336, Bench Warrant (2d Judicial Dist. Court, N.M. Aug. 12, 1999).

323. Letter from Wilhelmina Francisco Tengco, M.D., Psychiatrist of Jesse Martinez, to To Whom It May Concern (Sept. 1, 1999) (on file with the Georgetown Journal on Poverty Law & Policy).

324. Memorandum Of Telephone Conversation with Intake Worker, Hacienda Valmora, (Sept. 3, 1999).

325. *Id.*

326. *See id.*

and residential services in the Albuquerque area.³²⁷ The worker assigned to assess Jesse to determine his placement came from the residential treatment center that had prematurely discharged Jesse a few months before.³²⁸ The assessor set up an appointment to meet with Jesse in October 1999. She called two days later to cancel, stating that Jesse was already receiving all the services that were available to him.³²⁹ When pressed to do an assessment anyway, the worker said that finding a placement would be "very, very, difficult" and that if the insurance company denied payment, "there's not much we can do."³³⁰ The next friend again contacted the Managed Care Coordinator requesting all medically necessary services be provided to Jesse.³³¹

Another assessor came to meet with Jesse and recommended residential treatment.³³² On November 5, 1999, after weeks of incarceration at the D-Home, a neuropsychological exam was prepared. The report found that Jesse had feelings of depression and anxiety, suffered from occasional auditory hallucinations and that "an overall pattern of generalized cerebral impairment is indicated."³³³ The report recommended "a structured treatment environment that includes appropriate facilities for addressing someone with multiple cognitive impairments and that can address his mental health and substance abuse issues equally."³³⁴

Despite this clear indication that extensive mental health services were medically necessary, Jesse remained in detention center for several more weeks. On November 8, 1999, one of the attorneys representing Jesse in the class action wrote to the Medical Director of the Managed Care Organization, Options, asking them to "address the lengthy delay in providing appropriate mental health services to Jesse."³³⁵ The letter informed the Director,

[t]he staff there are not trained or able to address Jesse's mental health issues. The negative consequences of this inappropriate placement have been severe. Jesse has been routinely and severely punished for behaviors related to his disability. He has lost privileges, including being denied school services. Last

327. Letter from Executive Director, Children Adolescent, Adult and Family Consortium, to April Land (May 30, 2003).

328. See Memorandum of Telephone Conversation with Assessment Worker of the Consortium (Sept. 9, 1999).

329. Memorandum of Telephone Conversation with Assessment Worker of the Consortium (Oct. 4, 1999).

330. *Id.*

331. Letter from April Land, Next Friend to Jesse Martinez, to Arnold Schlosser, Presbyterian SALUD! (Oct. 4, 1999).

332. Memorandum of Telephone Conversation with Assessment Worker of the Consortium (Oct. 12, 1999).

333. CLINICAL NEUROPSYCHOLOGIST, NEUROPSYCHOLOGICAL EVALUATION (Nov. 5, 1999).

334. *Id.*

335. Letter from Tara Ford, Attorney for Jesse Martinez, to James Jacobson, Medical Director at Options (Nov. 8, 1999) (on file with the Georgetown Journal on Poverty Law & Policy).

week, he was seriously hurt by two staff members who were not trained to deal appropriately with Jesse's behaviors.³³⁶

On November 15, 1999, the managed care coordinator was contacted. He stated that he wished that the system were "more humane" but that the company had to look at resources. He indicated that day treatment was a "fairly high level of care" and suggested that a behavior management specialist might be appropriate.³³⁷ However, no behavior management specialist ever came to evaluate Jesse.

It appeared possible that a placement for Jesse had been found at a different residential treatment center in a rural area of New Mexico. On the cusp of Jesse's nineteenth birthday, the intake coordinator indicated that the state would not authorize the placement because he would lose his Medicaid coverage at age nineteen pursuant to the state plan. The limited time he would be in the program precluded his admission to the facility.³³⁸ Since Jesse had Medicaid Coverage through his Supplemental Security Income, his Medicaid coverage was mandatory and did not expire when he turned nineteen.³³⁹ Fortunately, the intake worker's misunderstanding was corrected through advocacy efforts, and Jesse was released from the detention center to the rural residential treatment center on December 20, 1999.³⁴⁰ This was three months after his treating physician wrote a letter stating that incarceration would worsen his mental health and that an alternative placement was critical.

Mr. Martinez became extremely concerned about Jesse's mental health when he saw Jesse at the rural treatment center. He was concerned that Jesse was not sufficiently medicated.³⁴¹ Jesse was behaving like a baby, curled up in a fetal position. In all of the years Mr. Martinez had been taking care of Jesse and visiting him in treatment centers, he had never seen him in such bad shape. Jesse called his probation officer and told her he felt unsafe in the facility because there were too many drugs in the facility. By January 28, 2000, Jesse was back in the D-Home.³⁴² The program coordinator for the facility said that Jesse probably never should have been admitted into this program because he was not

336. *Id.*

337. Memorandum of Telephone Conversation with Arnold Schlosser, Care Coordinator at Options (Nov. 15, 1999).

338. Memorandum of Telephone Conversation with Intake Coordinator, Hacienda Valmora (Nov. 1999).

339. See 42 U.S.C.A. §1396d(a)(i) (West 2003).

340. See *In the Matter of Jesse Martinez*, CHCH 95-2336, Order Of Release (2d Judicial D. Court, N.M. Dec. 20, 1999).

341. Memorandum of Telephone Conversation between Practicing Law Student, The University of New Mexico School of Law, and Patrick Martinez (Jan. 25, 2000).

342. The allegations made were that Jesse had threatened the staff. Jesse said that he was in a therapy session and the therapist had asked him to tell him honestly how he felt. Jesse said something threatening. Over a week later, after Jesse reported that kids were using drugs and escaping the facility, the facility contacted the Probation Officer to report the previous incident.

suited for it.³⁴³

The search for an appropriate placement for Jesse even led to the state mental hospital, which also includes an Intermediate Care Facility for the Mentally Retarded.³⁴⁴ The placement seemed to have been an appropriate placement for Jesse because it was a structured program designed for the care of people with similar cognitive challenges and backgrounds. However, the facility could not even consider taking Jesse because admission was limited to people with mental retardation who had already committed adult felonies.³⁴⁵

Despite several requests to the managed care company³⁴⁶ and continued class action litigation seeking services, neither alternative placements nor extensive mental health services were provided to Jesse. Lawyers defending against his claims for services moved for summary judgment on Jesse's claims. The grounds for the motion included the allegation that "J.M. has not been denied any benefit, service or equipment, which has been determined by any clinician to be medically necessary. In fact, the facts show that J.M. was approved for and placed into four different residential treatment facilities."³⁴⁷

F. Jesse's Experience Demonstrated the Failure of the State to Comply with Federal Medicaid Law

The state of New Mexico violated five vital mandates of federal law in failing to provide services to Jesse in his early teens, during the implementation of managed care and throughout the course of the class action suit.

1. Failure to Provide Medical Services in the Amount, Duration and Scope Necessary to Maximally Reduce His Mental Disabilities and Restore Him to the Best Possible Functional Level

In addition to the clear indications in Jesse's school records that Jesse needed mental health treatment, Jesse's medical records are replete with references to his need for extensive, long-term, mental health services. In 1997, when Jesse was sixteen, his doctors concluded that "[d]ue to the family history of mental illness, it is possible that Jesse will require long-term mental health treatment for several

343. Memorandum of telephone conversation with Zachary Ives (July 10, 2003).

344. See Draft Letter to Director, Las Vegas Medical Center (Apr. 26, 2000) (documenting trip to ICFMR on April 14, 2000 with practicing law students).

345. See Memorandum of Telephone Conversation with Social Worker, Las Vegas Intermediate Care Facility for the Mentally Retarded (Nov. 15, 1999).

346. See Letter From April Land, Next friend to Jesse Martinez, to Arnold Schlosser, Presbyterian SALUD! (Jan. 28, 2000) (on file with the Georgetown Journal on Poverty Law & Policy); see also Letter From April Land, Next Friend to Jesse Martinez, to Arnold Schlosser, Presbyterian SALUD! (May 12, 2000) (on file with the Georgetown Journal on Poverty Law & Policy).

347. Taylor v. Otten, No. CIV-98-1382 JC/DJS, Motion for Summary Judgment 3 (D.N.M. Aug. 1, 2000).

years to come.³⁴⁸ In 1998, at eighteen, Jesse was placed in a twenty-four hour-a-day structured treatment at Sequoyah, and it was recommended that the treatment be followed by "extensive community wrap-around services, including mental health, juvenile justice, and DVR, schooling (C.E.S.S.) programs."³⁴⁹ Again in 1999, a neuropsychologist evaluation recommended "a structured treatment environment that includes appropriate facilities for addressing someone with multiple cognitive impairments and that can address his mental health and substance abuse issues equally."³⁵⁰ Thus, according to Jesse's treating doctors and the specialists, it was medically necessary for him to be placed in a facility that could address his cognitive impairments, his mental health issues and his substance abuse issues, and that his discharge would involve intensive community, or "wraparound" services.

According to the lawyers defending the government in the Medicaid class action, there was "no legitimate basis" for the contention that Jesse was denied any benefit or service, citing the fact that he had been placed into four different treatment facilities.³⁵¹ The first residential center's treatment plan was to send Jesse to the D-Home.³⁵² Sequoyah, Jesse's second placement, discharged him although a treating psychiatrist felt the discharge was "bad for Jesse."³⁵³ Jesse was discharged to his home from the third placement despite the fact that placement at home was "not restrictive enough" as a long-term plan.³⁵⁴ The workers at the fourth placement stated that Jesse never should have been there. Further, residential services were not offered, and Jesse's need for extensive mental health services was not acknowledged. No community wraparound services were provided to Jesse upon his discharge from any of the facilities.

The response from almost every agency and treatment provider was that there was no appropriate placement for Jesse. As one provider indicated, Jesse is so disabled that he needs services, but the services "are not available."³⁵⁵ While the state is only required to provide services to the extent that they are available in the geographic area, such limited availability of care and services in the state should not relieve the state of its responsibility to provide necessary services.³⁵⁶ This is

348. NEW MEXICO DEPARTMENT OF HEALTH, SEQUOYAH ADOLESCENT TREATMENT CENTER, INTEGRATED SUMMARY (July 30, 1997).

349. NEW MEXICO DEPARTMENT OF HEALTH, SEQUOYAH ADOLESCENT TREATMENT CENTER, PREADMISSION EVALUATION (May 26, 1998).

350. ALBUQUERQUE PUBLIC SCHOOLS, NEUROPSYCHOLOGICAL EVALUATION (Nov. 5, 1999).

351. *Taylor v. Otten*, No. CIV-98-1382 JC/DJS, Motion for Summary Judgment 2-3 (D.N.M. Aug. 1, 2000).

352. DESERT HILLS CENTER FOR YOUTH AND FAMILIES, DISCHARGE SUMMARY 1-2 (May 31, 1998) (on file with the Georgetown Journal on Poverty Law & Policy).

353. Memorandum of Telephone Conversation between Practicing Law Student, The University of New Mexico School of Law, and Dr. Tolkusta, Treating Physician (Feb. 8, 1999).

354. Memorandum of Telephone Conversation with Case Manager, Hogares (Aug. 10, 1999).

355. Memorandum of Telephone Conversation between Practicing Law Student, The University of New Mexico School of Law, and Dr. Tolkusta, Treating Physician (Feb. 8, 1999).

356. See 42 U.S.C.A. § 1396a(30)(A) (West Supp. 2001).

especially true where the decreasing availability of care and services is the result of the state's adoption of a Medicaid system which created an incentive to reduce services. In a state where the vast majority of children are on Medicaid, the state should not be permitted to deny payment for treatment services—resulting in the closure of treatment providers—and then contend that the state does not have an obligation to provide services because of the limited facilities in the geographic area.

2. Failure to Provide Early Periodic Screening Diagnosis and Treatment

Federal law anticipates an aggressive effort to identify and treat children during their development to provide the most meaningful opportunity for treatment. However, Mr. Martinez faced difficulty in getting basic diagnostic screens for Jesse even after he had been identified as seriously emotionally disturbed. Jesse's medical records included three forms with EPSDT in the titles.³⁵⁷ Two were risk assessments.³⁵⁸ The other record, dated February 1998, described Jesse as developmentally "normal,"³⁵⁹ even though he had already been identified as having mental retardation.³⁶⁰ No referrals were made.³⁶¹ The failure to properly screen or assess Jesse led to the failure to provide adequate treatment: "Had he been provided with adequate treatment for his brain injury much earlier . . . J.M. could have learned compensatory behaviors."³⁶² No one ever offered to provide scheduling or transportation assistance to Mr. Martinez for Jesse. Mr. Martinez had not even heard of EPSDT until after the class action began, and did not know that the program required diagnosis and treatment until after Jesse had already died.

3. Failure to Provide Case Management

Case managers play a vital role in coordinating services, keeping track of appointments, and providing a sense of continuity of care through all of the systems of care delivery. A consistent case manager is also essential to long-term care and planning. For Jesse, "the lack of case management contributed to harmful multiple placements."³⁶³ Without an assigned case manager, Mr.

357. *Supplemental Report Regarding Medicaid Managed Care in New Mexico*, Feb. 21, 2000, Expert Report prepared for Taylor v. Johnson, No. CIV. 98-1382 JC/DJS, at 14 (prepared by Marty Beyer, Ph.D.).

358. *Id.* at 14-15.

359. *Id.* at 15.

360. MEMORIAL HOSPITAL, NEUROPSYCHOLOGICAL EVALUATION 2 (May 30, 1997).

361. *Supplemental Report Regarding Medicaid Managed Care in New Mexico*, Feb. 21, 2000, Expert Report prepared for Taylor v. Johnson, No. CIV. 98-1382 JC/DJS, at 12 (prepared by Marty Beyer, Ph.D.).

362. *Id.* at 11.

363. *Report Regarding Medicaid Managed Care in New Mexico*, Feb. 21, 2000, Expert Report prepared for Taylor v. Johnson, No. CIV. 98-1382 JC/DJS, at 30 (prepared by Marty Beyer, Ph.D.).

Martinez not only had to manage his mentally ill son's day-to-day needs, he had to spend hours negotiating with treatment providers in an attempt to secure basic services for Jesse. Case managers were provided while Jesse was in residential treatment facilities. However, once Jesse was released from treatment facilities, he did not have a case manager coordinating his care, despite repeated requests. Nor did he ever receive a notice that his request for the appointment of a case manager had been denied.

4. Failure to Provide Procedural Protections

While the procedural protections for Medicaid recipients are clear, the application of the right to a fair hearing is not clear. One of the roots of the failure of these provisions to protect children is the lack of coordination between the agencies responsible for providing services to children. Agencies and providers shift their responsibility for children to other agencies in a way that allows them to argue that there is no right to a hearing to challenge the transfer.

For example, when Jesse was discharged from a residential treatment center in 1998, Mr. Martinez unsuccessfully requested an administrative hearing to challenge the discharge. The discharge summary indicates that Jesse needed to be involved in the penal system for psychotherapeutic reasons; ironically, juvenile incarceration was his treatment plan.³⁶⁴ However, after his transfer from the residential treatment center to the D-Home, Jesse received no meaningful services for over a month. Mr. Martinez filed an administrative complaint to challenge the discharge and the reduction in services.³⁶⁵ The Hearing Examiner dismissed the complaint holding that the Department of Health and Human Services had no jurisdiction to hear the matter. The Hearing Officer held:

The change in Medicaid services available to Jesse Martinez while he was in detention was caused by the criminal, volitional acts committed by Jesse Martinez which ultimately resulted in the arrest of Jesse Martinez by court order, and such change in services was not caused by any action taken by HDS or its Medicaid contractor or subcontractor.³⁶⁶

Thus, the treatment decision to reduce services could not be challenged within the state administrative procedure.

Despite clear indications by the juvenile judge who placed Jesse in detention that Jesse would be released from detention as soon as appropriate treatment

364. DESERT HILLS CENTER FOR YOUTH AND FAMILIES, DISCHARGE SUMMARY 2 (May 31, 1998) (on file with the Georgetown Journal on Poverty Law & Policy).

365. Hearing Decision and Plaintiff's Record on Appeal at P1.2348 (Aug. 12, 1998); see Martinez v. Johnson, Appeal from the New Mexico Human Services Department, New Mexico Human Services Department, Administrative Hearings Bureau, Notice Of Dismissal Of Case No. 98-MC-007 (July 31, 1998).

366. *Id.*

could be secured for him, the Motion for Summary Judgment on Jesse's claims in the Medicaid class action argued that "J.M. could not have been removed from incarceration by either of the defendants and placed in an RTC."³⁶⁷ On these grounds, they sought dismissal of J.M.'s complaints.³⁶⁸

Managed care compounded the procedural difficulties. Jesse's next friend wrote letters to the managed care organization responsible for Jesse's care³⁶⁹ specifically attempting to start a formal grievance procedure. There was no reply to those letters. Managed Care attempted to avoid patients' procedural protections by negotiating with providers to recommend lower levels of service. For example, in Jesse's case, one assessor who came to visit Jesse when he was in the juvenile detention center recommended residential treatment. When he provided the assessment to the MCO, he was told to change his assessment to require a lower level of treatment. The assessor refused to change the assessment. But the only way that Mr. Martinez found out about the attempt to reduce the services was through Jesse's next friend's persistent questioning of a willing witness. Willing witnesses of this type are rare because the providers are dependent on their relationships with the MCOs and the BHOs for their very survival.³⁷⁰

5. Failure to Coordinate Efforts

From the beneficiaries' point of view, any coordination of efforts to provide services was difficult to discern. Mr. Martinez was directed from one department to another in the public education system, and in the Medicaid system, with no apparent coordination of services. Ultimately, when he was unable to secure meaningful long-term mental health treatment for his son, he was referred to and entangled in the juvenile justice system. Once involved in the juvenile justice system he was informed that his son could not get services through the juvenile justice system.³⁷¹

IV. THE JUVENILE JUSTICE SYSTEM REFLECTS THE FAILURES OF THE SPECIAL EDUCATION AND MEDICAID SYSTEMS

The breakdown in the delivery of mental health services, and the lack of procedural protections for Medicaid recipients under managed care, has led to an increasing proportion of children with serious emotional disturbance in the

367. Taylor v. Otten, No. CIV-98-1382, Motion for Summary Judgment, 3 (D.N.M. Aug. 1, 2000).

368. *Id.*

369. Letter from April Land, Next Friend To Jesse Martinez, to Arnold Schlosser and Leyla Pepper, Presbyterian SALUD! (Sept. 22, 1999).

370. See *Expert Report*, Feb. 21, 2000, prepared for Taylor v. Johnson, No. CIV. 98-1382 JC/DJS, at 32 (prepared by Neal Mazer, MD, MPH).

371. See Anne-Marie Cusac, *Arrest my Kid*, THE PROGRESSIVE (July 2001) (reporting on Mr. Martinez's efforts to secure treatment for Jesse and limited resources within New Mexico and the juvenile justice system).

juvenile justice system across the nation. A recent study funded by the National Institute of Mental Health found that managed care has led to increases in the number of children with mental illnesses incarcerated in the juvenile justice system, estimating that on any given day, approximately 106,000 teens are in custody in U.S. juvenile facilities, and that nearly two-thirds of boys and three-quarters of girls have at least one psychiatric disorder.³⁷² Another study found that while most youth in the juvenile justice system have a diagnosable mental illness and could benefit from some services, there is a sizeable group of youth who critically need access to mental health services because they are experiencing serious problems that interfere with their functioning.³⁷³ It is likely that more than half of adolescents in the juvenile justice system have a dual diagnosis.³⁷⁴

The findings of these studies are supported by the New Mexico experience.³⁷⁵ The utilization of inpatient psychiatric facilities by youth in the custody of juvenile justice is said to have doubled under SALUD! because children with serious emotional disturbance received inappropriate mental health treatment and then became involved with the juvenile justice system.³⁷⁶ The New Mexico Medicaid program's failure to provide adequate mental health services has been "a major cause" of the extended incarceration of children.³⁷⁷ Children are held in detention "for extended periods solely to wait for residential treatment, inpatient services, or outpatient care."³⁷⁸ Approximately one in seven youth in New Mexico's detention centers is incarcerated because mental health is not available.³⁷⁹ Representative Rick Miera (D-Albuquerque), who runs a drug and alcohol program for the Albuquerque's juvenile detention center, reported in September 2000 that an "increasing number of youths have serious mental health needs and often the only care they find is in jail When there is a shortage of places to refer them, judges are limited in what they can do with a child."³⁸⁰

372. Linda A. Teplin et. al, *Psychiatric Disorders in Youth in Juvenile Detention*, 59 ARCH. GEN. PSYCHIATRY 12 (2002).

373. JOSEPH J. COCOZZA & KATHLEEN R. SKOWYRA, U.S. DEP'T OF JUSTICE, JOURNAL OF THE OFFICE OF JUVENILE JUSTICE AND DELINQUENCY PREVENTION, YOUTH WITH MENTAL DISORDERS: ISSUES AND EMERGING RESPONSES 6 (2000) (citations omitted).

374. *Id.* at 6-7.

375. See THE TECHNICAL ASSISTANCE COLLABORATIVE, INC. & HUMAN SERVICES RESEARCH INSTITUTE, BEHAVIORAL HEALTH NEEDS & GAPS IN NEW MEXICO, Executive Summary Highlights ix and xxxiii (2002), available at <http://www.openminds.com/IndustryResources/bhsd1.pdf>.

376. *SALUD!'s Delivery of Mental Health Services; Problems and Recommendations: Hearing before the New Mexico Legislative Council Interim Health and Human Services Committee* (2000) (testimony of Rafael M. Semansky, MPP, Judge David L. Bazelon Center for Mental Health Law).

377. U.S. HOUSE OF REPRESENTATIVES COMMITTEE ON GOVERNMENT REFORM, SPECIAL INVESTIGATIONS DIVISION, MINORITY STAFF, INCARCERATION OF YOUTH WITH MENTAL HEALTH DISORDERS IN NEW MEXICO ii (2002), available at http://www.house.gov/reform/min/pdfs/pdf_inves/pdf_medi_nm_mental_health_rep.pdf.

378. *Id.* at i.

379. *Id.*

380. Jadnak, *Children in Crisis*, *supra* note 185, at A1.

Jesse's experience demonstrates the human costs of incarcerating children rather than providing necessary services and treatment. The juvenile justice system could not even begin to meet Jesse's mental health needs. His repeated trips to the juvenile detention center resulted in suicide attempts, long-term suspensions of his privileges within the detention center, and eventually transfer to the adult county jail. His experiences with the police and in the juvenile justice system reveal another lost opportunity to provide the services that were necessary to save Jesse's life.

A. Jesse's Rights in the Juvenile Justice System

Most of the protections for children in juvenile justice systems are federal constitutional rights,³⁸¹ and state statutory rights, which are beyond the scope of this Article focusing on federal statutory rights. However, Jesse's treatment in the juvenile justice system reflects the dramatic impact of the failure to provide meaningful treatment and services pursuant to the strong and clear federal protections for children.

Moreover, federal law requires the state agencies involved in the juvenile justice system to coordinate with special education³⁸² and Medicaid³⁸³ service delivery systems. Also state laws, including the New Mexico Children's Code, are clearly intended to coordinate efforts and protect children. The New Mexico Children's Code, which covers the treatment of children in delinquency proceedings states that its purpose is:

first to provide for the care, protection and wholesome mental and physical development of children coming within the provisions of the Children's Code . . . [and to] provide continuum of services for children and their families, from prevention to treatment, considering whenever possible prevention, diversion and early interventions, particularly in the schools.³⁸⁴

B. Jesse's Experience in the Juvenile Justice System

Jesse's contact with the juvenile justice system began early in his life, and demonstrated the State's failure to address his obvious mental health needs.

381. *Youngberg v. Romeo*, 457 U.S. 307 (1982) (persons with mental retardation have a substantive due process right to reasonable and reasonably non-restrictive care and to the training required by identifiable liberty interests); *Spivey v. Elliot*, 41 F.3d 1497 (11th Cir. 1995) (including when the government plays a dominant role in their lives); see also *Thomas S. v. Flaherty*, 902 F.2d 250 (4th Cir.), cert. denied, 498 U.S. 951 (1990); *Halderman v. Pennhurst State Sch. and Hosp.*, 784 F.Supp. 215, 222-23 (E.D. Pa.), aff'd, 977 F.2d 568 (3d Cir. 1992); *McNamara v. Dukakis*, 1990 WL 235439 (D. Mass. 1990).

382. See *supra* Section II.A.4.

383. See *supra* Section III.B.5.

384. N.M. STAT. ANN. § 32A-1-3 (Michie 1978, Supp. 2002).

1. Jesse Had Early Contacts with the Police and Juvenile Justice System

Mr. Martinez's first experiences with Jesse and the police gave him hope that it might be possible to secure services for Jesse through the delinquency system. One of the first officers to deal with Jesse was in charge of teaching recruits how to deal with mentally ill people. The family informed the officer that they were trying to get mental health services for Jesse. Later, the same officer picked Jesse up for smashing up the windows of an abandoned car. They were on route to the juvenile detention center when Jesse started violently banging his head against the window in a way in which he was likely to seriously injure himself. The officer sent for Mr. Martinez, let Jesse go, and told the family that he would try to help secure services for Jesse. However, the officer did not contact the family with any further information.

Jesse's serious entanglement in the juvenile justice system began as a result of two incidents. The first incident was when he was fourteen, in September 1995, shortly after his first suicide attempt. Jesse was at a friend's house where a group of kids were playing with a gun. The gun accidentally went off, shot through the window of the house and broke the window of a car that was parked outside of the house.³⁸⁵ A petition was filed against him on September 5, 1995, alleging that he had "shot at or from" a motor vehicle. It also charged Jesse with conspiracy to commit a shooting because he allegedly hid the rifle with the intent to prevent apprehension.³⁸⁶ A month later in October 1995, when he was still fourteen years old, Jesse was caught with crack cocaine.³⁸⁷ Jesse entered a plea to Negligent Use of a Firearm and Possession of Controlled Substance.³⁸⁸ He was placed on probation for a period "not to exceed two years" as a result of the plea.³⁸⁹ All of the other subsequent juvenile court proceedings were efforts to revoke that probation.³⁹⁰

The juvenile court judge wrote on the Probation Agreement: "[N]o tolerance on this case. Any violation must result in arrest."³⁹¹ The Probation Agreement and Order also directed the Juvenile Probation Officer (JPO) to make referrals to Case Management Collaborative and Innovative Services for possible ser-

385. See *In the Matter of Jesse Martinez*, CHCH 95-2336, Petition (2d Judicial D. Court, N.M. Sept. 7, 1995).

386. *Id.*

387. *In the Matter of Jesse Martinez*, CHCH 96-0285, Petition (2d Judicial D. Court, N.M. Feb. 5, 1996).

388. *In the Matter of Jesse Martinez*, CHCH 95-2336/96-285, Judgment and Disposition (2d Judicial D. Court, N.M. Mar. 27, 1996).

389. *Id.*; *In the Matter of Jesse Martinez*, CHCH 95-2336/96-285, Probation Agreement and Order (2d Judicial D. Court, N.M. Mar. 27, 1996).

390. See, e.g., *In the Matter of Jesse Martinez*, CHCH 95-2336/96-285, Petition to Revoke Probation (2d Judicial D. Court, N.M. June 27, 1996); *In the Matter of Jesse Martinez*, CHCH 95-2336/96-285, Petition to Revoke Probation (2d Judicial D. Court, N.M. July 11, 1997).

391. *In the Matter of Jesse Martinez*, CHCH 95-2336/96-285, Probation Agreement And Order (2d Judicial D. Court, N.M. Mar. 27, 1996).

vices.³⁹² Mr. Martinez does not recall any services being provided to Jesse at that time.

While on the streets, Jesse had to address the lawlessness of his neighborhood. He felt a responsibility to protect his friends and his brothers from violence. He repeatedly expressed concern about the possibility of his brother getting killed. He told one evaluator that his three magic wishes were to keep his brother at home to protect him from being shot.³⁹³

Jesse could not rely on the police for protection or safety. During his release, when he was still fifteen, Jesse was severely beaten by a police officer. Mr. Martinez recalls that Jesse had been in a pleasant mood the morning of the beating. Jesse had asked his father to stop at a store so that he could buy a plant as a present for his father's girlfriend. After buying the plant, Mr. Martinez dropped Jesse off to visit a friend. While Jesse was out on the porch of his friend's house, he saw a police officer, Felipe Rael, talking to a man across the street. The officer told the man to open up the trunk of his car, and the man responded that the officer had no right to make him do so. The officer became angry, and came across the street to the house where Jesse was standing on the porch. The owner of the house and the other witnesses later told Mr. Martinez that the officer had asked the owner of the house who Jesse was. Jesse said, "I am Jesse Martinez and I don't have any warrants, and I don't have any drugs." According to the witnesses, the owner's daughter then took Jesse into the house to avoid any confrontation with the officer. Over the owner's objections, the officer came into the house and tried to get Jesse to leave the house. Out of fear for Jesse based on the reputation of the officer, Jesse and the others refused to leave the house. The officer beat Jesse on the couch, in front of several witnesses, until Jesse began to bleed at the mouth. When Mr. Martinez arrived, the police had arrested Jesse. Jesse sat in the car, hitting his head against the window and pleading for help. Mr. Martinez pleaded with the police to take his son to the mental health hospital. The police instead took Jesse to the juvenile detention center where he was placed on suicide watch,³⁹⁴ and a Petition to Revoke Probation was filed.³⁹⁵

2. Jesse Demonstrated Clear Signs of Serious Mental Illness in Juvenile Detention

In June and July of 1996, when Jesse was fifteen years old, two additional petitions to revoke probation were filed against Jesse due to problems at home.³⁹⁶

392. *Id.* at 2.

393. ALBUQUERQUE PUBLIC SCHOOLS, PSYCHOEDUCATIONAL NEEDS EVALUATION (Nov. 6, 1996).

394. In the Matter of Jesse Martinez, No. CHCH 95 2336/96-285, Expedited Order (2d Judicial D. Court, N.M. Dec. 19, 1996).

395. In the Matter of Jesse Martinez, No. CHCH 95 2336/96-285, Petition To Revoke Probation (2d Judicial D. Court, N.M. Dec. 16, 1996).

396. In the Matter of Jesse Martinez, No. CHCH 95-2336/96-285, Petition to Revoke Probation, 1-2 (2d Judicial D. Court, N.M. July 22, 1996).

It was following the probable cause determination on these petitions that Jesse was detained,³⁹⁷ became suicidal, and tried to hang himself in the D-Home.³⁹⁸ He was taken to the University of New Mexico Hospital for treatment, and returned to the D-Home to face the petitions to revoke his probation. Mr. Martinez argued with the Public Defender who advised pleading to the charges. Eventually, Mr. Martinez prevailed at the trial on that petition, and the petitions that led to the suicide attempt were dismissed.³⁹⁹

Other petitions to revoke Jesse's probation were filed including a curfew violation; Jesse was "out of residence after 8pm."⁴⁰⁰ Jesse was held to be "in need or care or rehabilitation," and his probation was extended to two years from that date. Another arose over the beating by the police officer.⁴⁰¹ Another was filed alleging an assault on a police officer in December 1996.⁴⁰² The other petition during that period arose out of the allegations made by Memorial Hospital staff when Jesse's aggressive conduct was escalating; the hospital contacted the Juvenile Probation officer alleging that Jesse had taken "contraband" (a cigarette butt) into the facility.⁴⁰³

When he was sixteen, Jesse was evaluated for competency to stand trial on the petitions. According to the forensic evaluator, Jesse's public defender "reported that she did not have any real concerns about his ability to stand trial or enter into a plea agreement."⁴⁰⁴ The evaluator took a different view, finding that "his ability to sustain meaningful participation in proceedings in any length and complexity (e.g., a trial) would be in question."⁴⁰⁵ However, the report concluded that "based both on Jesse's attorney's observations and those gathered at the time of the evaluation, his ability to cooperate meaningfully on a one-to-one basis with her and to participate in more limited legal proceedings (e.g., a plea bargain) would seem adequate, if not optimal."⁴⁰⁶ Thus, despite the fact that legally, there is only

397. In the Matter of Jesse Martinez, No. CHCH 96-0285/CHCH 95-2336, Probable Cause Determination (2d Judicial D. Court, N.M. July 24, 1996).

398. See ALBUQUERQUE PUBLIC SCHOOLS, PSYCHOEDUCATIONAL NEEDS EVALUATION 5 (Nov. 6, 1996).

399. In the Matter of Jesse Martinez, No. CHCH 95-2336/96-285, Order (2d Judicial D. Court, N.M. Sept. 12, 1996) (stating that trial was completed on Sept. 12, 1996 and held, "child not guilty . . . petition is dismissed").

400. In the Matter of Jesse Martinez, No. CHCH 95-2336/96-285, Petition to Revoke Probation (2d Judicial D. Court, N.M. Oct. 23, 1996).

401. Jesse was charged with Battery on Police Officers, Escape from Peace Officer, Public Nuisance for concealing property and Receiving stolen vehicle. In the Matter of Jesse Martinez, No. CHCH 96-0285/CHCH 95-2336, Petition (2d Judicial D. Court, N.M. Dec. 16, 1996).

402. See In the Matter of Jesse Martinez, No. CHCH 95-2336/96-285, Petition to Revoke Probation, 1-3 (2d Judicial D. Court, N.M. Dec. 16, 1996).

403. See *id.*; In the Matter of Jesse Martinez, No. CH-95-2336/96-285, Probation Agreement and Order, 1-2 (2d Judicial D. Court, N.M. Nov. 7, 1996).

404. UNIVERSITY OF NEW MEXICO, HEALTH SCIENCES CENTER, PSYCHOLOGICAL EVALUATION REPORT 7 (May 14, 1997).

405. *Id.* at 9.

406. *Id.*

one standard for competency,⁴⁰⁷ the evaluator found Jesse incompetent to stand trial, but yet competent to plead guilty.⁴⁰⁸

The Forensic Report also stated that the alleged offenses seem to have occurred during a period of time when Jesse's home and family circumstances were chaotic, his mental and emotional problems were escalating, his judgment was at his worst, and he was most vulnerable to outside influences.⁴⁰⁹

Mr. Martinez was adamant that Jesse refuse to enter a plea to the charges arising from the beating by the police officer. Mr. Martinez was also concerned that Jesse was heavily sedated from the medications being administered to him. Nonetheless, over Mr. Martinez's objections, Jesse entered a plea of no contest to receiving stolen property and to charges related to the vehicle and bringing the cigarette into treatment.⁴¹⁰

As a result of the plea, Jesse was sent to the Sequoyah Adolescent Treatment Center on July 23, 1997.⁴¹¹ Mr. Martinez was glad that Jesse was going to get the treatment, but was upset that Jesse had pled guilty to the allegations in the Petition made by the treatment center. He felt that the hospital staff was punishing Jesse unfairly because they could not effectively address his mental health needs.

Jesse was unsuccessfully released to a day treatment program. The judge ordered that a behavioral specialist be assigned to monitor Jesse during evening hours.⁴¹² Mr. Martinez does not recall a behavioral specialist ever being assigned to Jesse at home in the evening, and it was not long before Jesse had to be hospitalized again.⁴¹³ When the hospital found Jesse too difficult to manage, they called the police. When the police refused to pick Jesse up and take him to the D-Home, the hospital convinced the Juvenile Probation Officer to issue a warrant for Jesse's arrest. The hospital considered incarceration to be part of Jesse's treatment plan,⁴¹⁴ and Jesse was returned to

407. See *Godinez v. Moran*, 509 U.S. 389 (1993) (holding that the standard of competency required to stand trial or to plead guilty is the same).

408. In the Matter of Jesse Martinez, No. CH-95-2336/96-285, Order Finding Child Incompetent to Stand Trial, 1 (2d Judicial D. Court, N.M. Oct. 1, 1999); UNIVERSITY OF NEW MEXICO, HEALTH SCIENCES CENTER, PSYCHOLOGICAL EVALUATION REPORT 9 (May 14, 1997).

409. *Id.* at 2-6 (discussing Jesse's background, clinical test results, and behavioral observations).

410. See In the Matter of Jesse Martinez, CHCH 96-0285/95-2336, Probation Agreement And Order (2d Judicial D. Court, N.M. July 17, 1997).

411. *Id.*

412. In the Matter of Jesse Martinez, No. CH-95-2336/96-285, Amendment to Probationary Agreement, (2d Judicial D. Court, N.M. Dec. 19, 1997).

413. One of the reasons for the gap between the Probation Agreement and the actual services that Jesse received may have been because of the transition to Managed Care. The juvenile court judges were accustomed to the fee-for-service Medicaid system, where they could order services, and the services would be provided without an additional determination by the managed care companies. Under Managed Care, providers required an independent evaluation of whether services were necessary. There was a period of time when the Children's Court judges were not aware of the change, and continued to order services.

414. DESERT HILLS CENTER FOR YOUTH AND FAMILIES, DISCHARGE SUMMARY (May 31, 1998) (on file with the Georgetown Journal on Poverty Law & Policy).

the D-Home.⁴¹⁵ The records reflect that Mr. Martinez went to the D-Home to express concern about Jesse's depression and asked that he be evaluated.⁴¹⁶

During his incarceration, Jesse slept excessively and reported hearing whispering voices.⁴¹⁷ He stated that he felt depressed and had thoughts about killing himself. Mr. Martinez was extremely concerned that Jesse would hurt himself, and discussed that possibility with the Children's Court Attorney. The Plea and Disposition Agreement entered on May 22, 1998 on the Petitions to Revoke Probation state that the "[Children's Court Attorney] agrees to conditionally release child to appropriate RTC when placement becomes available."⁴¹⁸ Jesse was still found to be in need of rehabilitation and his probation was extended to two years from July 1998. Jesse was then returned to a placement at Sequoyah, with instructions that he would be rebooked into the Juvenile Detention Home if discharged unsuccessfully from the program.⁴¹⁹

3. Jesse Suffered from Mistreatment While Incarcerated in Juvenile Detention

On August 21, 1998, when he was seventeen, Jesse was seriously injured while in treatment at Sequoyah.⁴²⁰ He had made a comment to one of his peers and was put in "time out." When he left the time out prematurely, a staff member restrained him. According to the staff member, Jesse "fell" during the containment.⁴²¹ According to Jesse, he was "tackled."⁴²² Jesse stopped breathing and had no pulse for five minutes.⁴²³ He was revived and transported to the University of New Mexico Hospital for one night.⁴²⁴ Mr. Martinez was seriously concerned about the incident, but he was more concerned that any action he might take against the staff at Sequoyah would result in Jesse's discharge, or in retaliation by staff against Jesse or his other children.

Mr. Martinez's concerns about retaliation were not unjustified. Many of the staff at Sequoyah also worked at the D-Home. Mr. Martinez had filed a Complaint against one such guard, for the way the guard had treated one of Mr. Martinez's other sons at Sequoyah. Jesse said that the guard kicked him in the face at the D-Home, and that just before the kicking him, the guard told Jesse that he had been waiting for the opportunity to kick Jesse for a long time.

415. See *In the Matter of Jesse Martinez*, No. CH-95-2336/96-285, Order, 1 (2d Judicial D. Court, N.M. Children's Court Div., May 5, 1997).

416. BERNILLO COUNTY JUVENILE DETENTION CENTER, DEPARTMENT OF ADOLESCENT MEDICINE, DOCUMENTATION (May 1, 1998).

417. See *id.* at May 2, 1998.

418. *In the Matter of Jesse Martinez*, CHCH 96-0285/95-2336, Plea and Disposition (2d Judicial D. Court, N.M. May 22, 1998).

419. *In the Matter of Jesse Martinez*, CHCH 96-0285/95-2336, Probation Agreement and Order (2d Judicial D. Court, N.M. July 7, 1998).

420. NEW MEXICO DEPARTMENT OF HEALTH, INVESTIGATION REPORT (Sept. 2, 1998).

421. *Id.*

422. *Id.*

423. *Id.*

424. *Id.*

Jesse's treatment during his periods of incarceration was troubling. He spent much of his time "off privileges," which meant that he was locked in his cell or pod for most of the day and was not permitted to go to school or engage in other activities. His privileges were suspended for acting out. On one occasion, Jesse's privileges were suspended because he had failed to line up in the proper line when the children were told to line up according to whether their numbers were odd or even. Jesse could not distinguish between odd and even. The staff was not appropriately equipped to address this kind of difficulty, and Jesse was often in trouble. Some staff members told Mr. Martinez that they were concerned for Jesse because other staff at the D-Home were taunting him.

Jesse was in and out of the D-Home from February to August 1999, when he began a long period of sustained incarceration. The juvenile court judge found that Jesse was incompetent to stand trial on October 1, 1999.⁴²⁵ The judge also found that Jesse met the criteria for pretrial detention.⁴²⁶ Aside from one month at a treatment center,⁴²⁷ Jesse was incarcerated at the D-Home from August 25, 1999 to February 11, 2000. Most of that time, he had already been found to be incompetent to stand trial on the petitions to revoke his probation.

On February 11, 2000 Jesse was still incarcerated at the D-Home and was having a mental health crisis. Jesse's next friend called the nurse at the D-Home to request that Jesse be transferred to a hospital for mental health treatment. The nurse said that it was not her call, but that she knew that "managed care will not take a referral."⁴²⁸ The next friend called and faxed the Managed Care Coordinator and requested that he work with the medical team to secure an appropriate treatment during the crisis.⁴²⁹ The Care Coordinator indicated that it was the MCO's job to make the necessary authorization only if requested by medical personnel.

4. Jesse Was Transferred to Adult Jail Despite His Severe Mental Illness and the Judicial Finding of His Incompetence to Stand Trial on Juvenile Charges

Jesse was transferred to adult jail. The Transportation Order specifically stated that Jesse was to be held "in the mental health unit."⁴³⁰ Two days later Jesse was

425. In the Matter of Jesse Martinez, No. CHCH 96-0285/95-2336, Order Finding Child Incompetent To Stand Trial (2d Judicial D. Court, N.M. Oct. 1, 1999) (finding Jesse to meet the "criteria for detention pursuant to Section 32A-2-11 of the Children's Code and the Children's Court Rule 10-209").

426. *Id.*

427. Jesse was placed at Hacienda Valmora from Dec. 20, 1999 to Jan. 26, 2000. In The Matter Of Jesse Martinez, No. JR 95-2336, Order of Release (2d Judicial D. Court, N.M. Dec. 20, 1999); In The Matter Of Jesse Martinez, No. JR 95-2336, Transportation Order (2d Judicial D. Court, N.M. 2d Judicial D. Court, N.M. Jan. 24, 2000).

428. Memorandum of telephone conversation with nurse at the D-home (Feb. 11, 2000).

429. Letter from April Land, Next Friend to Jesse Martinez, to Allan Schlosser, Presbyterian SALUD! (Feb. 11, 2000).

430. In The Matter Of Jesse Martinez, NO. JR 95-2336, Transportation Order (2d Judicial D. Court, N.M. Feb. 11, 2000).

placed in segregation at the adult jail. He was locked down twenty-three hours a day in the adult jail in a pod along with the most serious offenders.

Jesse was transferred back to the D-Home on February 22, 2000 for judicial review. At the hearing, the children's court judge made it clear that it was his opinion that Jesse's mental challenges were at the root of his behavioral problems and that he would order treatment as soon as placement became available. The judge ordered a forensic and competency evaluation.⁴³¹ Jesse was hearing people "whispering and talking about me, saying my name."⁴³² He "[saw] the wall moving, like it's breathing."⁴³³ Nonetheless, he was still in D-Home on February 27, 2000 indicating that he was only let out of his cell for two hours a day. An assessment recommended residential treatment for Jesse. No placement was forthcoming.

In February 2000 Jesse had been involved in an altercation at the D-Home. According to Jesse, the staff had told him that he could go watch a basketball game. When he lined up to go to basketball, they told him that he could not go. Jesse ran down the hall. The guard ran after him and tackled him. After Jesse was put in handcuffs, he allegedly spit at the guard. No charges were filed at the time, but the staff at the D-Home made it clear that they might file assault charges for that incident at any time.⁴³⁴

Over a month later, on March 22, 2000, when Jesse was nineteen, he was transported back to the adult jail allegedly for booking on adult assault charges arising out of the incident in February. A few more weeks went by and no charges were filed. Jesse was held in the general population at the adult jail. He was later transferred to a work release unit at the jail, even though he was not permitted to work. Thus, Jesse was held in the adult jail for almost two months, even though he had been found incompetent to stand trial on juvenile charges and had not had any adult charges filed against him. By April 14, 2000, Jesse was having a difficult time at the jail. He reported that he was miserable, depressed, frustrated, and wanted to know when he was getting out.⁴³⁵

On May 18, 2000, Jesse appeared before the juvenile court judge again. His public defender requested that the charges be dismissed based on Jesse's incompetence to stand trial.⁴³⁶ The prosecutor referred to the alleged assault charges with the guard, and requested that Jesse remain in custody.⁴³⁷ Mr. Martinez told the judge that his son was not ready for release. He told him that Jesse had significantly deteriorated because of the long-term incarceration and

431. In *The Matter Of Jesse Martinez*, NO. JR 95-2336, Order (2d Judicial D. Court, N.M. Feb. 22, 2000).

432. THE UNIVERSITY OF NEW MEXICO HEALTH SCIENCES CENTER, CHILDREN'S PSYCHIATRIC HOSPITAL, PSYCHOLOGICAL EVALUATION REPORT (Mar. 16, 2000).

433. *Id.*

434. See Memorandum of Telephone Conversation with Rick Miera (Feb. 24, 2000).

435. See Memorandum of Telephone Conversation with Jesse Martinez (Apr. 14, 2000).

436. Memorandum from Larry Kronen, Law Clerk, to Peter Cubra (May 19, 2000).

437. *Id.*

lack of meaningful treatment. Mr. Martinez pleaded with the judge for a transitional release plan, expressing concern that his son would not do well upon release given his current mental state.⁴³⁸ The judge replied, "we are not a mental health facility."⁴³⁹

Thus, the juvenile justice system failed to address Jesse's basic mental health needs. While incarcerated, he spent much of the time in lockdown or with his privileges suspended. He was beaten and taunted by guards and eventually transferred to the adult jail, where, at one point, he was held in lockdown, and at other times held in general population, even though he had been held incompetent to stand trial on juvenile charges and no adult charges were pending.

The juvenile judge found that he did not have authority to hold Jesse because Jesse was incompetent, and that it was not in his best interest to remain in detention.⁴⁴⁰ The court also found that Jesse's continued incarceration would be "a detriment to the residence and staff" of the detention center.⁴⁴¹ Jesse was released from detention on July 10, 2000, based on his incompetence to stand trial. Without any services upon his release, other than monthly visits with a psychiatrist who managed his medication, Jesse was back out on the streets within days. Within months, he was shot and stabbed in two separate incidents. In a little over a year after his release, Jesse was dead.

V. End of Jesse Martinez's Life

Prior to Jesse's release after almost a full year of incarceration, Jesse's next friend wrote a letter to the Managed Care Organization requesting all medically necessary services.⁴⁴² Other than medication management, no services were offered or provided. Jesse went straight back to the streets. He got picked up for shoplifting and another forensic evaluation was ordered in the adult system. Still, no services were provided.

Mr. Martinez saw his son deteriorating. In January 2001, days before his 20th birthday, Jesse was out on the streets and got into an altercation. He was stabbed in the neck, within inches of his jugular vein. He was released from the hospital with stitches in his neck. A few months later, he got into another fight and was shot in the hip. He pulled the bullet out of his leg himself, refusing treatment and refusing to call the police.

By late August 2001, Mr. Martinez was frantic about Jesse's mental health. He went to Jesse's treating psychiatrist and pleaded with her to fill out a civil commitment order that would require Jesse to be held for seventy-two hours of

438. *See id.*

439. *Id.*

440. In the Matter Of Jesse Martinez, No. JR 95-2336, Order of Dismissal (2d Judicial D. Court, N.M. July 10, 2000).

441. *Id.*

442. Letter from April Land, Next Friend to Jesse Martinez, to Allan Schlosser (May 12, 2000).

evaluation as a danger to himself and others, and be taken in for evaluation. Approximately two weeks prior to Jesse's death, Mr. Martinez went to see Jesse's psychiatrist again to plead with her. Mr. Martinez called to tell her that Jesse was deteriorating and that he did not know where he was and that he was in danger and that it was urgently important to get an order to pick him up. The psychiatrist said that she could do it, but it would be a "waste of time" because she had just done it for another patient, and that patient had been discharged shortly after the hold.

After Jesse's release, Mr. Martinez welcomed Jesse at home, and spent the better part of his life trying to track Jesse down on the streets. Jesse remained on the streets with no services, and sporadic medication, until he was killed. The following excerpts from the eulogy at his funeral captured the community response to his death.

[Jesse] possessed a rare kind of innocence. It was a quality given to him by God and a trademark of Jesse's that many of us will also remember. . . . Jesse is also a victim of the mental health system here in New Mexico that should have been able to protect him. Pat, along with Jesse's attorney worked hard to get help for Jesse. Jesse was even the subject of a magazine article written by Amnesty International. The sad fact is that the mental health system here in New Mexico failed to help Jesse and he ended up on the streets where his doctors feared he would not be able to survive. During the time Jesse was locked-up he was placed in solitary confinement, on and off for two months. On another occasion Jesse was beaten to the point of near death. Jesse was also able to acquire heroin while he was locked up. For a person like Jesse who didn't have the capacity to make the right choices, the odds were against him from the beginning.

It's hard to understand why some people must suffer as they do. Jesse had his share of hard times. We feel for him partly because of his innocent nature and also because we know what kind of person he really was . . .⁴⁴³

VI. COORDINATION OF CARE AND SERVICES IS ESSENTIAL TO MEET CHILDREN'S MENTAL HEALTH NEEDS

Children with disabilities and mental illnesses have clear statutory rights to treatment and education throughout their childhoods, and the agencies responsible for providing education and treatment are statutorily required to coordinate their efforts.⁴⁴⁴ However, rather than working together to provide a comprehensive range of services, the agencies and systems responsible for actually providing services direct parents and advocates for these children through an

443. Philip Martinez, Eulogy to Jesse Michael Martinez, Jan. 9, 1981-Sept. 12, 2001 (on file with the Georgetown Journal on Poverty Law & Policy).

444. 20 U.S.C.A. § 1412(a)(12) (West 2000); 42 U.S.C.A. § 1396a(a)(11)(A) (West Supp. 2001); 42 C.F.R. § 441.61 (2001); HEALTH CARE FINANCING ADMINISTRATION (HCFA) STATE MEDICAID MANUAL § 5230-5230.2, available at <http://cms.hhs.gov/manuals/pub45pdf/smm5t.pdf>.

endless, Kafkaesque maze of agencies. Each agency claims that another is responsible for providing services, and denies any ultimate responsibility for providing services; services that are not only vital to education, and medically necessary for "the restoration of an individual to the best possible functional level," but, as in Jesse's case, necessary to save his life.

The evasion of agency responsibility for the provision of education and treatment must stop. Coordination of care at every level, both within and between systems is vital to the successful delivery of education and mental health care for children with disabilities. The Surgeon General's National Action Agenda for Children's Mental Health calls upon the Nation to increase access to and coordination of quality mental healthcare services,⁴⁴⁵ and to "[m]onitor the access to and coordination of quality mental healthcare services."⁴⁴⁶ It specifically suggests the establishment of "formal partnerships among federal research, regulatory, and service agencies, professional associations and families and caregivers to facilitate the transfer of knowledge among research, practice, and policy related to children's mental health."⁴⁴⁷

A leading mental health advocacy organization, the Bazelon Center for Mental Health Law, also recommends that interagency collaboration be developed, not only at the state level, as required by federal law, but also at the federal level. In a study of interagency systems of care, the Bazelon Center found that the "fundamental problem is that the federal government appears to have developed no coherent cross-agency policy of its own and has not considered how its programs can complement each other to help a particular child."⁴⁴⁸ The study recommends cross-agency collaboration at the federal level to "foster greater blending or braiding of federal funds" in many ways, including the pooling of resources for pilot projects targeting children, establishing common federal indicators, and funding case managers across systems.⁴⁴⁹ These recommendations are supported by recent research concluding that:

[c]ross system collaboration must form the basis for all solutions. The field is beginning to understand that the needs and issues surrounding individuals with mental health disorders cannot be placed at the doorstep of any single agency or system Although an individual system can help to improve the care and treatment of youth with mental illness in the juvenile justice system, effective

445. U.S. PUBLIC HEALTH SERVICE, DEPARTMENT OF HEALTH AND HUMAN SERVICES, REPORT OF THE SURGEON GENERAL'S CONFERENCE ON CHILDREN'S MENTAL HEALTH: A NATIONAL ACTION AGENDA 9 (2000), available at <http://www.surgeongeneral.gov/topics/cmh/childreport.htm>.

446. *Id.* at 11.

447. *Id.*

448. Chris Koyanagi, *Help or Hindrance?: The Federal Government and Interagency Systems of Care for Children with Serious Mental Disorders* 3 (Feb. 2003), available at <http://www.bazelon.org/issues/children/publications/helporhindrance>.

449. *Id.* at 9.

solutions require that multiple relevant agencies coordinate and integrate strategies and services.⁴⁵⁰

As the Office of Juvenile Justice and Delinquency Prevention of the U.S. Department of Justice remarked concerning how to better provide mental health services to youth in the juvenile justice system, “[i]n order to maximize our efforts . . . we must work across disciplines through juvenile justice partnerships, with organizations serving children, families, and communities all working together. . . . Our children deserve no less than a full effort in this regard.”⁴⁵¹ The federal government, the states, the school boards and the Medicaid providers must coordinate efforts at every level to prevent children with disabilities from falling through the cracks and ending up in the juvenile justice system, in adult jails, and in early graves.

Recognizing that efforts to negotiate with the state and stakeholders to reform the Medicaid system in New Mexico were not successful, advocates from all agencies who work with children must still be encouraged to work with the state agencies. Advocates should work with state agencies to develop specific and meaningful interagency agreements regarding coordination of care. The Inter-agency Agreements and Memoranda of Agreement can clarify the responsibilities of each agency for providing key services, such as case management or care coordination. For example, a Model MOA developed for one federally funded IDEA program includes provisions requiring “the immediate assignment of a service coordinator,”⁴⁵² an intent to agree upon the selection, use and roles of the service coordinator, as well as a list of minimum responsibilities.⁴⁵³ Similar agreements in other programs may create mechanisms to encourage collaboration and stop the evasion of agency responsibility for providing required coordination of services.

Recognizing that complex federal class action litigation was not successful in remedying the crisis in mental health care in New Mexico, and that managing litigation on that scale can be unwieldy, lawyers need to continue to think

450. JOSEPH J. COCOZZA & KATHLEEN R. SKOWYRA, U.S. DEP’T OF JUSTICE, OFFICE OF JUVENILE JUSTICE AND DELINQUENCY PREVENTION, *YOUTH WITH MENTAL DISORDERS: ISSUES AND EMERGING RESPONSES* 7 (2000).

451. SALLY BILCHIK, U.S. DEP’T OF JUSTICE, OFFICE OF JUVENILE JUSTICE AND DELINQUENCY PREVENTION, *FACT SHEET 2* (1998). One successful project in Milwaukee pooled funds from child welfare and juvenile justice systems along with Medicaid and other Supplemental Security Income payments. With the use of intensive community based services and a focus on children’s individual needs, rates of delinquency in youth dropped dramatically, and the cost per child per month was reduced from \$5,000 to \$3,300. The collaboration between agencies was coupled with an emphasis on the assignment of care coordinators with small caseloads, which were found to be the cornerstone of the successful pilot project. Bruce Kamradt, *Wraparound Milwaukee: Aiding Youth with Mental Health Needs*, 7 JUV. JUST. J. 14, 18, 20 (2000), available at http://www.ncjrs.org/html/ojjdp/jjjnl_2000_4/wrap.html (last visited Apr. 11, 2003).

452. Early Access for Children and Families Program, Memorandum of Agreement, Western Regional Resource Center, University of Oregon 4, available at <http://interact.uoregon.edu/wrrc/wrrc.html>.

453. *Id.*

critically about how federal mandates to coordinate efforts can be enforced, both within systems and across systems. Avenues for exploration include focused litigation on statutory requirements to agencies to coordinate efforts,⁴⁵⁴ as well as efforts to develop theories of third party beneficiary claims⁴⁵⁵ to rights under the cooperative agreements into which states and agencies must enter to operate their programs.

CONCLUSION

The nation is facing a public crisis in mental healthcare for infants, children and adolescents There is broad evidence that the nation lacks a unified infrastructure to help these children, many of whom are falling through the cracks. Too often, children who are not identified as having mental health problems and who do not receive services end up in jail. Children and families are suffering because of missed opportunities for prevention and early identification, fragmented treatment services, and low priorities for resources.⁴⁵⁶

Children in poverty have clear, broad statutory rights to free and appropriate public education, and to all medically necessary services. Each of the agencies responsible for providing education and treatment of children with disabilities has its failings. These failings are compounded by the failure of each system to coordinate efforts to serve children.

Mr. Martinez's experience reflects the absence of any coordination of care between systems. He began his efforts to secure services for his son through the Special Education system. Despite the clear statutory mandate to provide a free and appropriate public education, and to provide the related services necessary for Jesse to benefit from his education, the educational system failed Jesse, informing Mr. Martinez that it was not equipped to serve Jesse. Mr. Martinez then sought treatment and services for his son through the behavioral health care system under his Medicaid coverage. While seeking services through the Medicaid system, he was informed that the only way to get treatment for his son would be through the juvenile justice system. Once involved in the juvenile

454. See Memorandum from Jane Perkins, Manju Kulkarni, and Lourdes Rivera, National Health Law Program, to Health Advocates re: Medicaid Managed Care Docket 9 (June 15, 2000) (discussing *Bates-Booker v. Houston*, No. 97-CV-3734 (E.D. Pa. 1997) (Agreement) ("Case involved interplay between Medicaid and special education services"), at <http://www.healthlaw.org/docs/MgdCareDocket.pdf>.

455. *Id.* (discussing *Brandie Hinds v. Blue Cross and Blue Shield of Tenn.*, No. 3:95-0508 (Dec. 28, 1995) ("found plaintiff had standing as a third party beneficiary to enforce specific contract provisions between BC/BS and TennCare regarding covered services")).

456. DEPARTMENT OF HEALTH AND HUMAN SERVICES, U.S. PUBLIC HEALTH SERVICE, REPORT OF THE SURGEON GENERAL'S CONFERENCE ON CHILDREN'S MENTAL HEALTH: A NATIONAL ACTION AGENDA (2000), at <http://www.surgeongeneral.gov/topics/cmh/childreport.htm> (last visited Apr. 10, 2003).

justice system however, Mr. Martinez was told that it was not a mental health system.

The juvenile judge recognized that Jesse's mental illness was at the root of his behavioral issues, and also found Jesse incompetent to face the charges against him, indicating a willingness to release Jesse to any appropriate mental health facility or treatment program. However, the state Medicaid system, through its lawyers, contended that Jesse could not have been removed from incarceration by either of the defendants and placed in a residential treatment center, and therefore his claim for Medicaid mental health services should be dismissed. Even when Jesse was placed in treatment centers, once a difficulty arose with Jesse or disagreement occurred between the treatment center and the family about Jesse's treatment or future, the treatment center would contact the juvenile justice system and Jesse would be returned to juvenile detention. Thus, Mr. Martinez's search for mental health services for his son led him from one agency to another, as each claimed that a different system was responsible for meeting Jesse's needs and as none provided the meaningful, long-term services necessary for Jesse to stay alive.

Each of the vital mandates under special education and Medicaid were violated throughout Jesse's life. He was not taught skills necessary to prepare him for independent living. He was not educated in the least restrictive environment. He did not receive medically necessary related services. Each system claimed a different system should be providing services. Rather than a seamless web of services, Jesse faced a piecemeal approach to the delivery of education and mental health services. Jesse fell through the gaping cracks between systems.

A few dedicated teachers went out of their way to help Jesse. But the school system, as a system, missed the opportunities to teach Jesse the skills he needed to stay alive. Some caring nurses and doctors advocated for Jesse to receive services. A couple of evaluators stood up to the managed care companies and insisted on their recommendations that Jesse receive more mental health treatment. But the Medicaid system failed to provide medically necessary services in the amount, duration and scope necessary for Jesse to stay alive. The lawyers defending the state missed an opportunity to work with advocates to help keep Jesse alive. The federal Health Care Financing Administration missed the opportunity to end the system that resulted in the crisis in behavioral health treatment.

The juvenile justice system failed to provide for Jesse's care and protection, much less his continued mental and physical development. Some people along the way cared about Jesse. The juvenile social worker at the public defender's office, the art teacher, and a guard at the D-Home fought for him to obtain services, and spoke out about his mistreatment. In addition, the juvenile court judge appreciated that Jesse's behavior was a product of his mental illness. But, the juvenile justice system missed an opportunity to work comprehensively with

other systems to ensure that Jesse received services. The juvenile system sent Jesse to jail.

Efforts must be made at every level to eliminate the gap between federal law mandates and the actual services that children can access. Federal agencies charged with overseeing Medicaid and IDEA should collaborate, and must enforce clear statutory requirements on the states. The federal government should not permit states to run Medicaid managed care systems that put federal funds targeted for children in the hands of for-profit companies, decreasing available treatment options and creating nightmares for treatment providers for children with chronic mental health needs. State agencies must work diligently to develop meaningful interagency agreements to ensure coordination of services. Lawyers must continue efforts to enforce strong legal protections through negotiation and litigation of individual cases, as well as large impact cases. Advocates and families of children with disabilities must continue to be vigilant in seeking services for their children with disabilities, and in organizing and supporting grass roots efforts to prevent and repeal state laws authorizing the implementation of Medicaid managed care and other state actions which reduce education and treatment opportunities for children with disabilities.

Despite the repeated and clear indications that Jesse needed extensive long-term mental health services to learn or to stay alive, too little was done to help him. If any one of the systems Mr. Martinez approached had provided services as required by law, Jesse might have been educated, might have been treated, and might be alive today. We will never know. It is too late now for Jesse. The broad, clear statutory rights that children have to mental health services must be enforced before it is too late for other children.