

IN THE UNITED STATES DISTRICT COURT  
WESTERN DISTRICT OF TEXAS, SAN ANTONIO DIVISION

XW and KRW, by their next friend AW, and	§	
BA, by his next friend, CB	§	
	§	
Plaintiffs,	§	
	§	
V.	§	CIVIL ACTION NO. 5:16-cv-1235
	§	
CHARLES SMITH, Executive Commissioner,	§	
Texas Health and Human Services	§	
Commission, and GARY JESSEE, Texas	§	
Medicaid Director, both in their official	§	
capacities only,	§	
	§	
	§	
Defendants.		

PLAINTIFFS' FIRST AMENDED COMPLAINT

INTRODUCTION

1. Plaintiffs are children who have been diagnosed with autism spectrum disorder. They appear through their adult next friends. They ask the Court to order Defendants to actually provide them with Applied Behavior Analysis treatment for their autism spectrum disorder and to inform them that Applied Behavior Analysis is available.<sup>1</sup>
2. Plaintiffs and their next friends bring this suit because Defendants do not provide Applied Behavioral Analysis as a Texas Medicaid benefit or inform anyone about it as a Medicaid benefit. 42 U.S.C. Sections 1396a(a)(43); 1396d(r). Through 42 U.S.C. Section 1983, Plaintiffs ask the Court to declare that Defendants violate their rights and to enjoin Defendants from depriving them of rights secured by the federal Medicaid Act.

---

<sup>11</sup> Plaintiffs' Lead Counsel did not number the paragraphs when she filed the Original Complaint in this case. She apologizes for this mistake. Plaintiffs file this First Amended Complaint only to add paragraph numbering. F.R.Civ. P. 10(b) (numbered paragraphs are required); F.R.Civ.P 15(a)(1)(amending as a "matter of course").

3. According to the United States Centers for Disease Control and Prevention, autism spectrum disorder (ASD)

is a developmental disability that is caused by differences in how the brain functions. People with ASD may communicate, interact, behave, and learn in different ways. Signs of ASD begin during early childhood and usually last throughout a person's life.... The term 'spectrum' in ASD means that each person can be affected in different ways, and symptoms can range from mild to severe. People with ASD share some similar symptoms, such as difficulties with social interaction, difficulties with communication, and highly focused interests and/or repetitive activities. How the symptoms affect a person's functioning depends on the severity and combination of those symptoms.

<http://www.cdc.gov/ncbddd/autism/documents/comm-report-autism-what-is.pdf>

4. The Texas Health and Human Services Commission told the Texas Legislature that Applied Behavior Analysis "is a treatment that uses behavioral principles to evaluate and teach socially relevant behavior and new skills and decrease undesirable behaviors through positive reinforcement. It is the most recommended, evidence-based treatment" for autism spectrum disorder. *available at* <https://hhs.texas.gov/sites/hhs/files/documents/about-hhs/communications-events/news/fy18-19-lar.pdf> at 3.A at 450 (hereinafter, LAR 2018-19).
5. It is medically necessary for each Plaintiff to receive Applied Behavior Analysis treatment.
6. The indigent Plaintiffs and their families cannot afford to pay for Applied Behavior Analysis treatment. The medically necessary dosage is normally 20-40 hours/week of treatment for several years.

#### JURISDICTION

7. This Court has jurisdiction over this suit. 28 U.S.C. Sections 1331, 1343.

VENUE

8. Venue is proper in this Court. 28 U.S.C. Section 1391(b)(2).

PARTIES

9. Plaintiffs XW and KRW appear by their next friend, AW. AW is the twin's mother and next friend in this case. They live together in San Antonio, Bexar County, Texas with their older brother. The twins qualify for Medicaid in Texas. XW's Texas Medicaid ID number is XXX-XX-6563. KRW's Texas Medicaid ID number is XXX-XX-6562.
10. Plaintiff BA appears by his next friend, BC. BC is BA's mother and next friend in this case. They live together in Bexar County, Texas with BA's father, brother and sister. Their father is a United States military veteran who served as a medic. Unfortunately, he was disabled following a vehicle roll over caused by an improvised explosive device (IED) while he was in the service. BA qualifies for Medicaid in Texas. His Medicaid ID number is XXX-XX-1211.
11. Defendant Charles Smith is the Executive Commissioner of the Texas Health and Human Services Commission. The Texas Health and Human Services Commission is Texas' "single state agency", which administers the Texas Medicaid Program. 42 U.S.C. Section 1396a(a)(5). Defendant Smith may be served with process at the Texas Health and Human Services Commission, Brown-Heatly Building, 4900 N. Lamar Blvd., Austin, TX 78751-2316. Plaintiff sues Defendant Smith in his official capacity only, and seeks only injunctive relief, declaratory relief and attorneys' fees.
12. Defendant Gary Jessee is the Texas Medicaid Director. He may be served with process at the Texas Health and Human Services Commission, Brown-Heatly

Building, 4900 N. Lamar Blvd., Austin, TX 78751-2316. Plaintiff sues Defendant Jessee in his official capacity only, and seeks only injunctive relief, declaratory relief and attorneys' fees.

## FACTS

### Plaintiffs XW and KRW

13. Plaintiffs XW and KRW are 5 year old twin brothers. They were born prematurely in April, 2011. In May, 2016, both were found to have autism spectrum disorder during evaluations to determine if they qualify for special education services for children with disabilities. Further, psychologist Andrew Martinez, PhD, confirmed the diagnosis in the fall of 2016.

### XW

14. XW's mother describes him as a loving, funny, cute child. He shows interest in books and he likes to run and jump. He is active and easily distracted.
15. XW was born prematurely. At birth, he only weighed about 3 pounds. He has an oral aversion; even though he is already 5 years old, he does not eat any solid food. XW receives all nutrition by drinking a nutritional supplement (Boost) from a bottle. Sensory disorders, such as oral aversion, are common among people with autism spectrum disorder.
16. XW's expressive and receptive speech are in the below average range. He can speak in 2 word phrases but he cannot yet speak in 3 word phrases. He also babbles and repeats phrases in a manner known as echolalia, which is common among people who have autism spectrum disorder.

17. XW is not toilet trained. He needs adult assistance to wash his hands. He does not dress himself.
18. Both the special education evaluation and Dr. Martinez' evaluation show that XW has severe autism spectrum disorder. Both evaluations also show that his intellectual development is significantly below the norm for children of his age.
19. It is medically necessary for XW to receive up to 40 hours of Applied Behavior Analysis every week for several years.

KRW

20. KRW's mother reports that he is also loving, funny, cute and generally happy. He likes to play with toy cars.
21. KRW was born seconds before XW. At birth, he weighed about 6 pounds.
22. Like his twin, KRW is an active child and easily distracted.
23. When upset, KRW sometimes exhibits self-injurious behaviors, which is common among people with autism spectrum disorder. For example, KRW exhibits head banging. He also slams himself into walls or doors.
24. KRW is not toilet trained.
25. Although KRW's speech is somewhat more developed than his brother's, both his receptive and expressive speech are in the below average range.
26. The evaluations by the school and Dr. Martinez both show that KRW has mild to moderate autism spectrum disorder. His intellectual functioning is below the norm when compared to other children of his age.
27. It is medically necessary for KRW to receive up to 40 hours of Applied Behavior Analysis for several years.

28. Plaintiffs XW and KRW started to receive very limited Applied Behavior Analysis services in the summer of 2016. They receive these limited services through Defendants' focused Applied Behavior Analysis program, which is described in more detail below. The program does not meet their needs because it is limited to 30 hours/month and 6 months out of a year. The twins need 30-40 hours/week of Applied Behavior Analysis, and they will need ongoing treatment for several years.
29. Defendants' focused Applied Behavior Analysis services are not a Medicaid benefit.

BA

30. CB had suspected for a long time that her son, BA, had a medical problem that impaired his social functioning. But it was not until BA was in the third grade that a doctor confirmed her suspicions. At that time, a new pediatrician determined that something was wrong.
31. The new pediatrician, Syliva Leal, MD, referred BA for an evaluation to find out if he had autism spectrum disorder in late 2014. It took until June 2016 for BA to be seen at the Multidisciplinary Autism Clinic at the Children's Hospital of San Antonio.
32. Each member of the multidisciplinary team enjoyed working with BA. They found BA to be "delightful and pleasant" and noted that his family is very supportive of him.
33. The Clinic diagnosed BA with autism spectrum disorder. Their intellectual functioning evaluation showed that BA does not have an intellectual disability although his intelligence is in the low-normal range.
34. Proper Applied Behavior Analysis treatment could enable BA to function independently in school, in the community and at home.

35. The Clinic concluded that BA

is smart and this bodes well for his prognosis. We feel that ABA (applied behavioral analysis) therapy would be very good for [BA] to focus on social skills and to improve his restricted, repetitive behaviors. However, this can be very difficult to get as Medicaid will not cover this. However, if he is able to get it, he would greatly benefit, so we have given information on scholarships to cover this therapy.

#### Plaintiffs Requested Assistance

36. XW and KRW requested Medicaid coverage of an adequate amount of Applied

Behavior Analysis by letter to Defendants' Chief Counsel on October 11, 2016. BA also asked the Chief Counsel to approve Applied Behavior Analysis by letter on October 28, 2016. To date, the Chief Counsel's Office has not responded.

#### Autism Spectrum Disorder

37. Autism spectrum disorder is a developmental disability evidenced by impairments in social relations and communication as well as restricted interests, repetitive behaviors. Sensory disorders are also fairly common. There is significant variation among people who are diagnosed with autism spectrum disorder in terms of the severity of the condition and the symptoms displayed.

38. According to the Texas Health and Human Services Commission, the

“Center for Disease Control and Prevention reported that in 2015, approximately 1 in 68 children in the U.S. had a diagnosis of autism spectrum disorder (ASD). Based on these numbers, it is estimated that there are more than 157, 780 [...] children ages 3 through 15 with ASD in Texas in 2016. The number is projected to increase, growing to approximately 159,449 in 2017.”

LAR 2018-2019 at 3.A. at 140. The “increasing number of children diagnosed with autism has created a national health emergency in the United States. Autism is more

common than childhood cancer, juvenile diabetes, and pediatric AIDS combined.” *Id.* at 450.

39. About 1 in 42 boys suffers from autism spectrum disorder; about 1 in 189 girls receive the diagnosis.

40. Some children with autism spectrum disorder also have intellectual disabilities but others do not. According to the Centers for Disease Control and Prevention, about 44% of children with autism spectrum disorder have cognitive function that is average or above average.

41. The cause of autism spectrum disorder is not fully understood. Genetics plays a role but this role is not clear cut. Other factors are important, including parents’ advanced age at conception and problems during pregnancy and delivery.

42. There is not yet a cure for autism spectrum disorder.

#### Applied Behavior Analysis

43. Applied Behavior Analysis has been studied for several decades. It is the gold standard, evidence-based treatment for children with autism spectrum disorder. Although Applied Behavior Analysis cannot cure autism spectrum disorder, it can alleviate symptoms – or help children to cope with symptoms - so that some children with autism spectrum disorder go on to live normal, productive lives.

44. Applied Behavior Analysis is performed by Board Certified Behavior Analysts (BCBAs), who are certified by the Behavior Analyst Certification Board. To sit for the certification exam, applicants must graduate from an approved graduate program at an accredited university, complete sufficient graduate course work in behavior analysis, and complete a supervised practicum. BCBAs are trained to evaluate the

strengths and weaknesses of children with autism spectrum disorder. Based on that evaluation, they develop, implement, evaluate and recalibrate Applied Behavior Analysis treatment plans for children with autism spectrum disorder. BCBAs also teach families to help children with autism spectrum disorder.

45. Applied Behavior Analysis uses proven behavioral treatments to improve the ability of children with autism spectrum disorder to function in real life situations by reducing the frequency of problem behaviors and increasing the frequency of functional behaviors. Applied Behavioral Analysis uses learning theory to intervene to alter behavior using frequent repetition of expectations, positive reinforcement of desired behaviors, incremental change in small behaviors over time and recalibration of the treatment plan over time as behavior changes. It includes daily documentation to show if interventions cause improvement so that if an intervention is not appropriate, it can be changed. In short, “ABA is a treatment that uses behavioral principles to evaluate and teach socially relevant behavior and new skills and increase desirable behaviors through positive reinforcement.... The team that develops the plan assesses progress and adjusts it to address the child’s needs and strengths.”

LAR2018-2019 at 3.A. at 450. Since children with autism spectrum disorder vary a lot in their symptoms, Applied Behavior Analysis treatment plans are specific to the needs of each child.

46. Among children with autism, Applied Behavior Analysis has been shown to improve global function in the areas of communication, interpersonal relationships, learning, self-regulation, adaptability and lessening of maladaptive behaviors. If children receive good Applied Behavior Analysis for long enough, some can function

normally without other support in school, at home and in the community. LAR 2018-2019 at 3.A. at 140. Others will continue to need ongoing support.

47. Children with autism spectrum disorder require about 20-40 hours/week of Applied Behavior Analysis, usually for several years. This level and extent of service is necessary to help children with autism spectrum disorder to develop and/or improve the full range of life skills that they often lack.
48. “Focused Applied Behavior Analysis” is another form of the treatment. As implied by its name, this form of treatment focuses on one or a few interrelated harmful behaviors. While focused treatment can be helpful when used appropriately, it is not adequate to address the broad range of maladaptive behaviors found among children with autism spectrum disorder.
49. Although Defendants do not offer Applied Behavior Analysis at all as a Medicaid benefit, they offer very limited *focused* Applied Behavior Analysis treatment to 3-15 year olds with autism spectrum disorder through grants. The program is, however, limited. It only provides **up to 30 hours of services per month for no more than 6 months/year**. Some children with autism spectrum disorder regress after services end.
50. The focused program is also limited because it serves only a very small number of Texas children with autism spectrum disorder. Even according to the Defendants, Applied Behavior Analysis is “still not available in all areas of the state, and there continues to be significant need.” LAR 2018-2019 at 3.A. at 140.
51. The numbers support Defendants’ conclusion that in Texas there is significant unmet need for Applied Behavior Analysis treatment. Defendants estimate that in FY2016,

they will provide even their very limited focused services to only 657 children. They hope to expand the service to help 1114 children in FY2018 and 2019. LAR 2018-2019 at 3.A. at 138. Since more than 150,000 Texas children have autism spectrum disorder, Defendants' limited program served less than 4% of children in need of Applied Behavior Analysis in 2016..

52. Defendants used to also offer more extensive Applied Behavior Analysis for children with autism spectrum disorder, with 20-40 hours of treatment/week for more than a year at a time. But, they phased out this more adequate comprehensive treatment program. "As of September 1, 2015, the program began only enrolling new children in Focused ABA treatment...." LAR2018-2019 at 3.A. at 451.

#### Texas Medicaid Program

53. Medicaid is a cooperative federal-state program. The federal government provides funds to states to furnish health care services to indigent individuals. If a state opts to accept federal Medicaid funding, it must comply with federal requirements, including those set out in this Complaint.

54. State Medicaid programs must identify a "single state agency" to run its Medicaid program. 42 U.S.C. Section 1396a(a)(5). The Texas Health and Human Services Commission is Texas' single state agency.

55. The Center for Medicare and Medicaid Services (CMS) at the United States Department of Health and Human Services is the federal Medicaid agency.

56. Defendants' policy is that Applied Behavior Analysis is not a covered benefit of the Texas Medicaid Program. Defendants do not inform anyone about Applied Behavior Analysis as part of their Medicaid informing efforts.

Congress Intends That Plaintiffs Are Entitled to Receive Applied  
Behavior Analysis Treatment

57. Medicaid assistance “means payment of part or all of the cost of the following care and services *or the care and services themselves*, or both....” 42 U.S.C. Section 1396d(a)(emphasis added). In other words, Congress intends that Medicaid recipients like Plaintiffs are entitled to actually receive “care and services” as well as payment to their health care professionals for those services.

Early, Periodic Screening, Diagnosis and Treatment (EPSDT):  
A Mandatory Medicaid Service for Children

58. Defendants must provide “early and periodic screening, diagnostic, and treatment services” for Medicaid recipients up through the age of 21 years. 42 U.S.C. Sections 13969a(A)(43); 1396d(r)(“EPSDT”)(emphasis added). As part of EPSDT, Defendants must provide “[s]uch other necessary health care, diagnostic services, treatment, and other measures described in [42 U.S.C. Section 1396d(a)] 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.” 42 U.S.C. Section 1396d(r)(5) (emphasis added). Applied Behavior Analysis is an EPSDT service because it is necessary health care to correct or ameliorate defects and illnesses and conditions.

59. Indeed, on July 14, 2014, CMS issued an Informational Bulletin entitled Clarification of Medical Coverage of Services to Children with Autism. It reaffirmed that EPSDT is “intended to ensure a comprehensive, high-quality health care benefit for eligible individuals under the age of 21, including for those with [autism spectrum disorder], based on individual determinations of medical

necessity.... [For Medicaid recipients under the age of 21 years,]... the expectation [is] that EPSDT will meet the individual's needs.”

60. The EPSDT section of the Medicaid Act creates rights that can be vindicated via 42 U.S.C. Section 1983. First, Congress clearly intended to confer rights on individuals under the age of 21, like Plaintiffs; the Medicaid Act requires Defendants to provide EPSDT services to “all persons in the State who are under the age of 21 and who have been determined to be eligible for” Medicaid. 42 U.S.C. Section 1396a(a)(43).
61. Further, the EPSDT section of the Act is neither vague nor amorphous. Enforcement would not strain the competence of this Court or any other Court. Plaintiffs ask the Court to determine that they are entitled to one specific treatment: Applied Behavior Analysis, which is a covered service included in the EPSDT benefit. Sections. 1396a(a)(43); 1396d(r)(5).
62. Last, Congress requires Defendants to provide Applied Behavior Analysis for Plaintiffs. For Medicaid recipients under the age of 21 years, Defendants “must ... provide ... “ EPSDT services. 42 U.S.C. Section 1396a(a)(43). Further, Section 1396a(a)(43)(A) states that the full scope of services is defined in Section 1396d(r), mentioned above. Section 1396(d)(r)(5) requires Defendants to provide a broad range of health care services to Medicaid recipients under the age of 21, including Applied Behavior Analysis.

Defendants Must Make Medical Assistance “Available”

63. Defendants “must ... provide for making medical assistance available, including at least the care and services listed in paragraphs (1) through (5), (17) and (21) of section 1396d(a) of this title, to all individuals...” who qualify for Medicaid. 42

U.S.C. Section 1396a(a)(10)(A)(i). Applied Behavior Analysis is covered in the EPSDT provisions of the Medicaid Act. EPSDT services are listed in the 4<sup>th</sup> paragraph of Section 1396(d)(a). The 4<sup>th</sup> paragraph further refers to Section 1396d(r), which defines the broad scope of services that Defendants must provide to Plaintiffs, including Applied Behavior Analysis.

64. Section 1396a(a)(10)(A)(i) of the Medicaid Act creates rights that can be vindicated via 42 U.S.C. Section 1983. Congress clearly intended to confer rights on individuals who qualify for Medicaid, such as Plaintiffs. Indeed, Section 1396a(a)(10)(A)(i) states that Defendants “must ... mak[e] ... medical assistance available ... to all individuals who qualify for Medicaid.”

65. Further, it is well within the Courts’ competence to enforce Section 1396a(a)(10)(A)(i). As stated above, Plaintiffs seek to require Defendants to make available to them only one treatment: Applied Behavior Analysis. This is not vague or amorphous.

66. Finally, Congress certainly requires Defendants to provide Applied Behavior Analysis to Plaintiffs. Section 1396a(a)(10)(A)(i) is phrased in mandatory terms: Defendants “must ... provide for making medical assistance available...” including EPSDT services. Section 1396a(a)(43); 1396d(r)(5).

Defendants Must Inform Plaintiffs That Applied  
Behavior Analysis Is A Covered Medicaid Benefit

67. Defendants “must ... provide for— informing all persons in the State who are under the age of 21 and who have been determined to be eligible for medical assistance ..., of the availability of early and periodic screening, diagnostic, and treatment services as described in section 1396d(r) of this title....” 42 U.S.C. Section 1396a(a)(43)(A).

Defendants have not informed anyone about Applied Behavior Analysis as a Medicaid benefit, as required by law.

68. Section 1396a(a)(43)(A) of the Medicaid Act creates rights that can be vindicated via 42 U.S.C. Section 1983. Congress clearly intended to confer rights on children who qualify for Medicaid, such as Plaintiffs. Indeed, Section 1396a(a)(43)(A) states that Defendants “must ... provide for informing all persons who are under the age of 21 and who have been determined eligible for Medicaid,” which includes Plaintiffs.

69. Further, it is well within the Courts’ competence to enforce Section 1396a(a)(43)(A). Plaintiffs seek to require Defendants to inform them about only one thing: Applied Behavior Analysis as a Medicaid benefit. This is not vague or amorphous.

70. Finally, Congress certainly requires Defendants to inform Plaintiffs about Applied Behavior Analysis as a Medicaid benefit included within EPSDT. Section 1396a(a)(43)(A) is phrased in mandatory terms: Defendants “must ... provide for - informing... ..” about EPSDT services, including Applied Behavior Analysis. Section 1396a(a)(43); 1396d(r)(5).

#### REMEDIES SOUGHT

71. Plaintiffs seek relief to require Defendants to 1) change their policy to cover Applied Behavior Analysis as a Medicaid benefit when medically necessary, 2) actually provide Applied Behavior Analysis when medically necessary, as it is for the Plaintiffs in this case, and 3) inform Plaintiffs and others about Applied Behavior Analysis as a covered benefit of the Medicaid program to assist them to actually receive services that they need. Further, Plaintiffs ask the Court to declare that Defendants violate their rights granted by the Medicaid Act. They also ask the Court

to enjoin Defendants to actually provide Applied Behavior Analysis to them and to inform them about this Medicaid service. 42 U.S.C. Sections 1396a(a)(43); 1396d(r); 42 U.S.C. Section 1983; 28 U.S.C. Sections 2201 and 2202; Federal Rules of Civil Procedure 57 and 65. They also seek to recover attorneys' fees, costs and expenses. 42 U.S.C. Section 1988; FRCivP 54(d).

#### FIRST CLAIM FOR RELIEF

72. Defendants violate Plaintiffs' right to EPSDT services by failing to provide the Applied Behavior Analysis that they need, in violation of 42 U.S.C. Sections 1396a(a)(43) and 1396d(r)(5). They may seek relief from the violation of their rights. 42 U.S.C. Section 1983.

#### SECOND CLAIM FOR RELIEF

73. Defendants violate Plaintiffs' right to have "available" Applied Behavior Analysis, in violation of 42 U.S.C. Sections 1396a(a)(10); 1396a(a)(43); 1396d(r)(5). Plaintiffs may seek relief from the violation of these rights. 42 U.S.C. Section 1983.

#### THIRD CLAIM FOR RELIEF

74. Defendants violate Plaintiffs' right to information about Applied Behavior Analysis as a Medicaid benefit, in violation of 42 U.S.C. Sections 1396a(a)(43)(A). Plaintiffs may seek relief from the violation of these rights. 42 U.S.C. Section 1983.

Accordingly, Plaintiffs, through their next friends, seek the following relief:

- a. That the Court assert jurisdiction over this case and the Defendants;
- b. That the Court require Defendants to be served and to respond;
- c. That the Court permit reasonable discovery to Plaintiffs;

d. That the Court declare that Defendants have violated Plaintiffs' rights created by the Medicaid Act;

e. That the Court enjoin Defendants from violating Plaintiffs' rights created by the Medicaid Act;

f. That the Court require Defendants to reimburse Plaintiffs' attorneys for reasonable attorneys' fees, costs and expenses of this litigation; and

g. That the Court grant all further relief that is justified by law and in equity.

Respectfully Submitted,

Susan F. Zinn  
Texas Bar No. 07015500  
TEXAS RIOGRANDE LEGAL AID, INC.  
Medical Legal Assistance for Families  
Mailing address: 1111 N. Main Street  
San Antonio, TX 78212  
Tel: (210) 704-8730  
Fax: (210) 704-8743  
[szinn@trla.org](mailto:szinn@trla.org)  
Plaintiffs' Attorney in Charge

Peter Hofer  
State Bar No. 09777275  
DISABILITY RIGHTS TEXAS  
2222 West Braker Lane  
Austin, Texas 78758  
(512) 454-4816 (Phone)  
(512) 454-3999 (Fax)  
[phofer@drtx.org](mailto:phofer@drtx.org)

Attorneys for Plaintiffs XW and KRW by  
their next friend AW, and BA by his next  
friend CB

BY: /s/ Susan F. Zinn