

## About the Author



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## Autistic Children on Medicaid Missing Out on Crucial Therapy

A dark-haired, seven year old Florida child from an impoverished family, called K.G. in court papers, recently struck a blow to eliminate one of the most unjust health care disparities in America.

At 18 months, K.G. was diagnosed with autism. K.G. banged his head against a wall, bit himself, incessantly threw tantrums, barely made eye contact or spoke more than two or three words, and isolated himself from other children. His only hope was a therapy known as Applied Behavioral Analysis, long considered by every authoritative voice in American pediatric health care, from the U.S. Surgeon General to the Centers for Disease Control, to be the one effective treatment for autism disorders. Indeed, 34 states, including Florida, require commercial insurance plans to cover the cost of this therapy for children and adolescents.

K.G.'s parents could not afford either commercial insurance or the therapy. They applied to the Florida Agency for Health Care Administration, which administers the state Medicaid program, to cover the therapy's costs. The agency denied the application on the ground that the therapy was "experimental." K.G.'s only alternative was the disabilities "waiting list," where the average wait time for medical assistance was at least five years.

In 2011, K.G. and his parents filed a federal civil rights lawsuit against the agency. Later that year, Miami Federal Judge Joan Lenard preliminary ruled that the therapy was not experimental and directed the agency to immediately cover the costs of K.G.'s therapy, pending a

final hearing.

As revealed at the final hearing in 2012, after the first month of therapy, K.G.'s kicking, biting and hitting, which occurred 60 times during a three-hour session at the initial assessment, had decreased to zero. He slept better, smiled, said "hello" to people, and even spoke in sentences. "I am seeing again the baby that I had, happy and smiling," his mother testified, "a baby that I lost." But, terminating the therapy "would be catastrophic. It is a law of life that I'm not going to be eternal. What kind of future is he going to have?"

Calling the case "one of the most important that I have ever heard," Judge Lenard ordered the agency to continue covering the cost of K.G.'s therapy, and to make it available to other Medicaid-eligible autistic

children in Florida. The agency appealed to the U.S. Court of Appeals for the 11<sup>th</sup> Circuit, which, in September 2013, substantially affirmed the permanent injunction. While Florida finally must cover the therapy under Medicaid, the state legislature's refusal to expand Medicaid eligibility under the Affordable Care Act means that many autistic children from low-income families still will not receive it (Ohio, by contrast, both accepted expanded Medicaid and will make the therapy available to the newly eligible families with autistic children).

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Most states refuse to provide coverage for the therapy under Medicaid, other than through waiting lists. Autistic children from families able to afford commercial insurance, or to independently pay the cost, will receive the therapy. Their futures will be immeasurably brighter. One study demonstrated that 40% of the children receiving the therapy at an early age did not require any treatment after they reached school age.

But for autistic children from most poor families the future is grim. They will live with limited functionality, dependent in one way or another on community and state or federal government support. Many will be institutionalized. In fact, the cost of their maintenance will exceed the cost of the therapy.

At the final hearing, Judge Lenard heard testimony about the agency's failure to comply with a modest state legislative mandate to do a feasibility study of providing Applied Behavioral Analysis to young children. The tragedy of autistic children caught in a bureaucratic labyrinth crystallized for her. She asked the agency's lawyers, "They were supposed to complete it [the study] by 2009. We are now in 2012. How many children were lost?"

Until this terrible health care disparity is ended, it's a question that should haunt us all.

*Gregory Wallance filed an amicus curiae brief in the 11<sup>th</sup> Circuit on behalf of autism advocacy organizations in support of K.G.*

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