

Testimony Before the Senate Judiciary Committee
re. Supreme Court Nomination of Judge Neil Gorsuch

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The Boy
Julie Perkins, 2000

There is a little boy, who is very dear to me.
He's trapped inside a world, that only he can see.

Some nights I hear him crying and there's nothing I can do;
My heart sorrows with him, for this way he did not choose.

He is loved by many others, not just his family.
They've helped us see a glimpse of the boy that he could be.

My prayer is as I hold his gentle hand,
That one day the love of God he will understand.

He isn't just another face or just another name,
He's the boy who makes us thankful, and this is why he came.

I am honored to give this testimony on behalf of my son, Luke Perkins. As an individual severely affected by autism, his access to an appropriate education and thus to a meaningful and dignified life were threatened by the views of Judge Neil Gorsuch, as expressed in the opinion that he authored as a judge on the U.S. 10th Circuit Court of Appeals in 2008.

[Luke's Infancy and Early Childhood](#)

My son, Luke Joseph Perkins, was born on October 29, 1994 at Johns Hopkins Hospital in Baltimore, Maryland. Luke's development seemed normal for the first several months of life. He began arm flapping at the age of 10 months, initially as a sign of excitement when watching his favorite TV character, Barney the Dinosaur. We did not realize the significance of this behavior, a common "self-stimulatory" behavior in autistic children, until later. We began noticing that his language was significantly delayed, compared to his older brothers.

On February 28, 1996, at 16 months of age, Luke underwent a Brainstem Auditory Evoked Response test – a hearing test for children unable to cooperate with the standard hearing screening. The result of the test was normal – he was not hearing impaired. At first this was great news. But then, the realization of the implications of this began to sink in. If Luke wasn't hearing impaired, there had to be another reason for his failure to talk.

After multiple evaluations, first in Baltimore and then in our new home in Colorado, Luke was diagnosed with autism by Dr. Sally Rogers on September 3, 1996, at the age of 22 months. Dr. Rogers began an

intensive early childhood intervention program, modeled on what the “applied behavioral analysis” approach. She met with Luke and Julie on a weekly basis. Julie and Luke worked one-on-one for several hours per day. In the sessions, Luke would sit across from Julie in a tiny wooden chair with substantial arms. This way, he would stay sitting forward. The concept behind applied behavioral analysis is simple: give a command, prompt the child to follow the command, and reward the child for his behavior. Luke’s rewards at first were food: Fruit Loops were his favorite. When Luke started this program, he never made eye contact and did not respond to his name. He made rapid progress. Within a matter of weeks, under the expert guidance of Dr. Rogers, Julie had taught Luke to consistently make eye contact with the command, “Luke, look at me.”

Over the next few years, Luke learned many things, including many commands, the names of body parts, colors, numbers and letters. By far the hardest thing for Luke was speech. Dr. Rogers pulled out all her tricks, but Luke seemed to have virtually no awareness of or voluntary control over the muscles used for speech.

In March of 1997, we hired the first of several home teachers to help with Luke’s program. The hours of intense effort and concentration needed to maintain Luke’s program started wearing on Julie and on our whole family. Luke was still showing no real signs of verbal communication, though there was clearly a sharp intelligence buried beneath the dense web of his autism.

Luke had only a very limited set of interests. Watching Barney videotapes was first among them. He had virtually no ability to entertain or occupy himself. Luke’s older brothers, Titus and Jacob, did their best to interact with Luke. But Luke treated them, as he treated everyone else, like a piece of furniture. He even went so far at times as to arrange people in rows, just like he did with toys or food.

Public School: Preschool through 1st Grade

In March 1998, we moved into the St. Vrain School District and met Margaret Wilson, a brilliant and compassionate special educator with a special interest in autism. The focus of Luke’s education gradually shifted from Dr. Rogers and home therapy to a school-based program.

Under Margaret’s guidance, Luke made a successful transition into kindergarten at Niwot Elementary School in the fall of 2000. Luke loved school. It was so predictable and structured, in a way that home could not be with 3 other siblings (Luke had a baby sister in 1998). With Margaret’s knowledgeable leadership, Luke was successfully integrated into a typical kindergarten classroom and accepted by his teachers and peers. Margaret and her team of para-educators went the extra mile to work with and teach Luke. Though still not talking much, he was learning every day and he was happy, especially at school. He was even beginning to use several intelligible word approximations to communicate. Somewhat frustrating from our perspective was Luke’s inability to generalize much of his speech and other positive behaviors from school to home.

Home life

At home, progress was more mixed and uneven. Luke’s taste in food, always limited, became gradually more and more restricted. His highly-preferred foods included crackers, mustard and yogurt. Most foods that a normal child his age would eat were steadfastly refused. His day-night cycle became ever more erratic. Ever since Luke outgrew his crib, he has had the lock reversed on his bedroom door. While the

idea of locking our son in his room at night bothered us a lot, Luke's disturbed diurnal cycle and his ever growing capacity for mischief made this decision mandatory.

Toilet training was a never-ending process. He was doing fairly well at school by 1st grade, but still had frequent accidents during the day at home. Nighttime continence was a distant dream at best. His awareness of his own internal bodily signals was virtually nonexistent.

In 2001, Luke began having more significant negative behaviors. While still happy and easygoing most of the time, he began to experience tantrums. Several medications were tried to help with sleep and tantrums, but either were ineffective or had significant side effects.

Gradually, Luke's behavior restricted his activities and the activities of his family. Trips to the store became first hard, then impossible. While Luke had grown up since infancy going to church every Sunday, his behavior in church became more and more unpredictable. Finally, people at church began volunteering to stay with Luke so that the rest of the family could worship in peace. Simple things to most families, such as dinner at a restaurant or going to a movie, took major planning and preparation.

Caring for Luke, along with the rest of our family, became too much for us to handle on our own. In order to maintain the functioning of our family, we needed some help. So, in 2001, our family of six moved in with my parents for a year. We then bought adjoining plots of land in Weld County and built two houses so that my mother could be nearby to help with Luke and the other kids.

One of the main design considerations in our new house was Luke. We had special sliding locks installed on all outside doors that Luke could not reach. There were locked cabinets built into the floor plan in the kitchen and living room. We had extra reinforcement and insulation in the floor of Luke's bedroom to withstand the jumping. We had a TV/VCR player put into his room behind thick plastic. His bedroom window was made out of safety glass. His closet door had a keyed lock. There was even a large eye bolt screwed into a reinforced beam in his ceiling from which to suspend his favorite hammock swing.

Throughout this difficult time, Luke's one consistent bright spot was school. The imposed structure and caring, competent teachers and staff seemed to bring a measure of peace and order to his tangled mind. We had bought our land in Weld County just after Luke started kindergarten. We discovered that our land was in the Thompson Valley school district. At the time, this did not seem to be a big deal. We naively assumed that all schools had someone like Margaret Wilson to guide the education of their autistic students.

The Berthoud Years: 2nd and 3rd Grade

As the end of Luke's 1st grade year at Niwot Elementary approached, we began looking toward transitioning Luke into his new school. A meeting was held between Luke's Niwot Elementary team and two representatives from the team that would be taking over his education in his new school. We were somewhat concerned by the seeming lack of interest and initiative displayed by the incoming team. For example, despite the fact that the meeting was held in a conference room less than 100 feet from Luke's classroom, neither of the new team members even asked to see Luke.

We petitioned twice to keep Luke in his former school via the open enrollment process, but were rebuffed by the Thompson School District, due to financial considerations and wanting to avoid setting a precedent for other disabled children.

So, we pressed ahead with enrollment into Berthoud Elementary. At first, things seemed to go fine. Luke still seemed to enjoy school, based on the feedback that his teacher gave in his daily notebook. However, we began noticing that Luke was losing skills. He pointed less and his limited verbal skills began slipping noticeably. Toward the end of his second grade year, his behavior began taking a significant turn for the worse at home.

Luke did not tolerate a parent observing at school. In his mind, parents were for home and teachers for school. In order to better understand what was going on at school we sought help from Diane Osaki, an occupational therapist who had worked with Luke at the beginning of his therapy and who now runs the Aspen School. As part of her evaluation, Ms. Osaki requested to visit Luke at Berthoud Elementary. When we met with Ms. Osaki after her visit, we were dismayed to hear the extent of Luke's behavioral problems at school. These included a majority of his time being spent in tantruming, oppositional activity and even throwing of computer equipment. Ms. Osaki described an environment where there was complete lack of a reasoned, consistent behavioral or educational approach. In fact, the responses of the staff to his inappropriate behavior were reinforcing and not extinguishing it. Looking back in his daily notebook on the day that Ms. Osaki visited his school, there was no notation of any behavioral problems. We realized at this point that we had been naïve in our assumption that we were being given an accurate report of his progress at school.

Considering Other Options

As he started into 3rd grade in the fall of 2003, his behavior at home deteriorated to the point that we feared that he would become a significant danger to himself, his siblings and his mother in the not too distant future. We began to investigate our options. Given Luke's difficulty generalizing skills from school to home, and his worsening behavior issues, we considered the possibility of residential schools. At first, the idea of sending our 8-year-old son to live away from home was very difficult. However, as we investigated more, we realized that placement in a school where he could be exposed to consistent behavioral and educational methods in a seamless environment might be his best chance for achieving educational and behavioral progress. It became clear quickly that there were no facilities in or around Colorado that would be able to provide an appropriate residential environment for his education.

Since our triennial IEP meeting was approaching, we decided to attempt to address our concerns with the local school district one last time at this meeting. The meeting did not go well. The educators seemed oblivious to Luke's needs, and did not suggest any significant changes to his program. After this meeting, our decision was made. We could not in good conscience continue to expose Luke to this environment that was so detrimental to his educational and behavioral development. We made the decision to enroll Luke at the Boston Higashi School, a unique school in Boston dedicated to the education of children with autism spectrum disorders.

Boston Higashi School

Boston Higashi School was founded in 1987 by Dr. Kiyoko Kitahara, a Japanese educator who had experienced significant success in educating students in Japan with her method, called Daily Life Therapy. Daily Life Therapy is founded upon three major premises. First, stability of emotions is gained through the pursuit of independent living skills and the development of self-esteem. Second, extensive physical exercise is used to establish a rhythm of life. This inhibits anxiety through the release of endorphins, as well as reducing aggression, self-stimulatory behavior and hyperactivity. Physical exercise

with a group of students also serves as a bridge to the development of social skills. Third, the intellect is stimulated through instruction in language arts, mathematics and social sciences in a group academic setting with an age appropriate curriculum. Behavior is controlled through non-medical means, and students at Boston Higashi School are not allowed to take medications for the purpose of behavior control.

Luke was accepted into the Intermediate Elementary division of Boston Higashi School on December 18, 2003. He was to begin as soon after the winter break as possible.

When Luke left for Boston in January 2003, he slept in a locked room with no bed, never slept through the night and was not toilet trained. He ate a very restricted, unhealthy diet and received very little physical exercise. He had very underdeveloped gross and fine motor skills and could not dress himself or help in any of his activities of daily living. He had long since ceased to learn in his present academic environment, and was losing previously acquired skills at an alarming rate. Most alarmingly, his behavior was on a course that would soon make it impossible to stay in public school due to safety concerns, and might ultimately make it impossible for him to live at home with his family.

Leaving Luke at Boston Higashi School that first time was gut wrenching. We met with his day and residential teachers and dropping off his clothes. We were told that he would not be needing the large suitcase of adult-sized diapers at this new school. We were incredulous, given that Luke had failed so many attempts at toilet training over the years. After telling Luke goodbye, we returned to Colorado, leaving our son in the capable hands of the staff at Higashi.

Luke made astounding progress in many areas. Within a few weeks, he was sleeping in his bed through the night on a consistent basis. Toilet training also went very smoothly. In music class, he gradually learned to tolerate previously intolerable levels of noise. Within his first year, he was playing "Mary Had a Little Lamb" on a keyboard harmonica.

His progress in eating and feeding himself was truly remarkable. Due to the boundless patience and dedication of his classroom teacher, Fuyu, he was eating a wide variety of healthy foods in the dining hall every day, such as soup, salad, meat and vegetables with proper utensils.

In academics, he was in a small class, with a total of 4 to 6 students. He learned quickly to sit in a normal student desk. He learned subjects such as arithmetic, geometry and reading.

Regular physical activity is an important part of the Higashi method. He gradually learned to jog with his classmates. In addition, he learned to do such things as ride a unicycle and walk on stilts. These activities honed his underdeveloped gross motor and balance skills. On the residential side of his schooling, he learned to participate in recreational activities, such as rollerblading and bowling.

One of the most appealing features of the Boston Higashi program was three breaks during the year, totaling eight weeks, where students would go home and reconnect with their families. When Luke came home for the first few breaks, he had trouble generalizing all of his learned skills from school to home. However, with time, skills learned at school translated to home. His ability to participate in family and community life increased significantly. We could shop together, eat at a restaurant together, and even attend church together.

Legal Battles

But this improved life for Luke was costly. Despite my comfortable income as a physician, Luke's education costs rapidly depleted our reserves. My parents contributed a substantial amount from their retirement savings. However, even with this, we could not continue to pay his tuition indefinitely. In January 2005, we requested reimbursement for Luke's education under the Individuals with Disabilities Education Act.

A Due Process Hearing was held in June. This was a 5 day hearing in a conference room at the school district offices. Presiding over the hearing was the Independent Hearing Officer (IHO). The IHO found in our favor, and instructed that the Thompson School District begin paying for Luke's education at the Boston Higashi School.

Over the next few years, this decision was appealed by the school district, first to an administrative law judge and then to the U.S. District Court. Both of these appeals upheld the original decision. The IHO, administrative law judge and District Court judge all ruled that while Luke made very small gains in some academic areas, his behaviors were deteriorating, he was regressing in his communication and daily living skills, and he was not able to transfer those few academic skills outside of the classroom. Each of these judges concluded that such little educational benefit from the public school could constitute an appropriate education under the IDEA.

10th Circuit Court of Appeals

In 2007, the school district appealed to the 10th circuit. The final ruling was issued in August 2008. This decision, authored by Judge Neil Gorsuch, overturned all of these previous rulings. His legal reasoning set a new, low standard of education required under IDEA. There were two specific areas in which his ruling lowered the working definition of a free and appropriate public education.

First, taking the phrase "more than *de minimis*" from a 1996 10th Circuit decision (*Urban v. Jefferson County Schl. Dist.*), he recontextualized this phrase and added the word "merely." In articulating that a public school must provide an education under IDEA that is "merely... 'more than *de minimis*,'" Judge Gorsuch changes the *de minimis* standard from one that must always be exceeded to a goal for which a school district may legitimately aim. The term *de minimis* is defined as follows: "lacking significance or importance: so minor as to merit disregard." Judge Gorsuch felt that an education for my son that was even one small step above insignificant was acceptable.

Second, Judge Gorsuch sets a novel standard in this ruling of "some progress" in the student's achievement of educational goals. Thus, despite Luke's inability to meet three quarters of his educational goals in his individualized education plan, or to use any of these skills outside the classroom, the "progress" noted on 25% of the goals was felt to be evidence that his education was appropriate. This standard, rather than a standard of "some educational benefit," makes proof of an appropriate education by a public school *pro forma*. All that a school would need to do is to document some progress on a single goal to meet this standard. Even if a child, as in Luke's case, was utterly failing to progress in any meaningful global sense, the educational plan would be judged "appropriate."

Aftermath

The 10th Circuit decision was devastating to us. By this time, Luke had been at Boston Higashi School for five years, and his overall progress was nothing short of dramatic. The possibility that Luke would lose the ability to continue in this very successful educational placement was unthinkable. However, once our petition to be heard by the Supreme Court was denied, we had no other legal avenues to challenge the Thompson School District educational plan.

We worked with the school district in 2010 to devise an acceptable program for local back home. We then enrolled Luke in this program, with careful observation of his progress. It became clear within a few weeks that nothing substantive had changed. Luke would quickly lose the progress that he had made over his several years at Higashi if he stayed with the School District's program. Rather than risk Luke's losing all of his hard-fought educational gains, we removed him from his placement in the Thompson School District and re-enrolled him at Higashi. However, we had only enough money to pay for one more year of education.

This left us with only one real option. One of Luke's parents would have to move to a school district that would better accommodate Luke's educational needs. Practically, that meant moving to Massachusetts. Since I was geographically tied to my medical practice in Colorado, the only option was for Julie to move. After much prayer and thought, my wife decided to permanently relocate to Dedham, Massachusetts. Thankfully, the Dedham School District acknowledged Luke's extraordinary needs, allowing him to finish out his time at Higashi.

Now aged 22, Luke will always need support in a world that still seems perplexing and threatening to him. But his quality of life after 13 years of appropriate education is vastly better than it would have been otherwise. He cooks and does household chores. He is able to shop, work, eat and play in the community. And he has developed a new passion— Legos. Luke's mind is uniquely attuned to this plastic brick world. He constructed a model in January 2017 of the U.S. Capitol Building with over 1000 pieces. His present life would not have been achievable without an appropriate education.

Thankfully, Luke is unaware of the price paid for his education. The financial cost pales in comparison to the human sacrifice: his mother separated from her 13-year-old daughter; his parents' marriage broken. He is also unaware of the key place that one judge, with his radically restrictive interpretation of law, played in the fight for his right to a free and appropriate public education.

In his 10th Circuit ruling, Judge Gorsuch eviscerated the educational standard guaranteed by the IDEA. His interpretation requires that a school provide a disabled child an education just above meaningless. And his novel standard of "some progress" sets the bar so low that meaningful benefit is often denied to students with impunity, even as their child's education plan is failing utterly when viewed globally. Legal philosophy and case law aside, such an interpretation clearly fails the common sense test. Why would Congress pass a law with such a trivial intent? And why would a parent settle for such an education for any of their children – regardless of their abilities or challenges?

On behalf of all children – disabled, typical and gifted – I urge you to deny confirmation of Judge Neal Gorsuch to the Supreme Court of the United States.