

## Children, adults with non-verbal learning disorder develop strategies for using talents, navigating around deficits

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Steve Hockstein/For The Star-LedgerArlene and

Harold Shapiro, owners of Meyer's Dolls, Toys and Hobbies display a copy of their grandson's book about coping with Non-Verbal Learning Disorder, at their store in Livingston.

Before the age of 1, J.C. could hum Brahms' lullaby and the theme from "Jeopardy." At 2, he could name the U.S. presidents in order and recognize their faces.

A month before he turned 5, he was at a Bergen County restaurant where, to the astonishment of his parents, not to mention the other diners, he performed the opening scene from "The Lion King," eerily imitating the accents and intonations of James Earl Jones and Jeremy Irons.

Though his grandparents — naturally — insisted he was gifted, his parents knew that J.C.'s extraordinary talents co-existed with some serious deficits. He had difficulty following directions, and his teachers complained that he asked too many questions; he was highly verbal but very repetitive; he struggled with simple motor tasks; he was terrified of transitions and novel situations and often misperceived his parents' moods or intentions. And though he loved being around other children, he played alongside them rather than with them.

He didn't seem to "get" the give and take of friendship that most kids learn by osmosis.

After nearly 14 exhausting years of child study team meetings and psychological evaluations, J.C., now a 23-year-old student at a New Jersey college, was diagnosed with nonverbal learning disorder, a neurological condition that impairs the ability to process nonverbal information.

Considering that gestures, touch, body language, facial expressions and eye contact make up roughly two-thirds of all human communication, experts say, and that communication is essential to the learning process, the impact of NLD can be devastating.

"Kids with NLD don't 'look and learn,' so they need to be specifically taught — in words — what most people learn automatically," says Judy Lewis, an educator and coach based in Carmel, Calif., who runs the website NLDline.com and whose many New Jersey clients have included J.C. and his parents.

"That's why they often have huge gaps in their knowledge that those who understand the syndrome are constantly working to fill."

Think of the NLD brain as a chunk of Swiss cheese, with the nonverbal information slipping through the holes. But the verbal information clings to it like a warm baguette, giving people with NLD a tendency to be extremely articulate.

And that, Lewis says, is precisely what makes their lives so difficult. "They are so verbal and often so bright that they appear super-competent," she says. "So the expectations are incredibly high for these kids — and adults — who have so many problems just getting through the day."

Like children with Asperger syndrome, with which this disorder sometimes co-exists and shares many traits, youngsters with NLD have significant difficulty acquiring social skills because of their inability to read nonverbal cues. They have social and emotional problems on top of their academic challenges, which, without effective interventions, worsen as they mature and learning becomes more abstract and conceptual.

**Living with nonverbal learning disorder** Fenton Turck of Cliffside Park has NLD, Nonverbal Learning Disorder, a neurological condition that impairs his ability to process nonverbal information. Gestures, touch, body language and facial expressions make up about two-thirds of all human communication, so living with the syndrome can be extremely difficult. For Turck, NLD is not something you suffer from. It just means you have a different way of viewing the world. (Video by Adya Beasley / The Star-Ledger)

Complicating matters further, NLD is frequently masked by the many syndromes accompanying it, including obsessive-compulsive disorder, anxiety disorders and behavioral problems.

And the same difficulties seen in NLD, such as planning, prioritizing and organizing, are common in disabilities such as attention-deficit disorder.

"Even now, in college, I ask my tutors to treat me like I'm in kindergarten," says J.C., who asked that his full name not be printed because his struggles embarrass him. "I often don't know where to begin with complex assignments ... Everything needs to be broken down for me."

The worst part, says J.C., who has excelled academically with extra support and tutoring, is that "people don't understand why I don't understand."

### **SOMEONE WHO GETS IT**

Michael Murphy understands, and he knows firsthand that J.C. has enough company to fill a book. Murphy, 29, is the author of "NLD From the Inside Out: Talking to Parents, Teachers and Teens About Growing Up With Nonverbal Learning Disabilities." Based on an online survey of young people with NLD, the book — its second edition has just been released — includes the latest neurological research, as well as tips on everything from finding the right therapist to getting a date.

"After all I've experienced, I thought it was my mission to get information out to a population that is so misunderstood," says Murphy, a Wayland, Mass., native with what he calls "plenty of Jersey street cred." (His mother and stepfather are from Millburn, where his grandparents still reside.)

### **"NLD From the Inside Out: Talking With Parents, Teachers and Teens About Growing Up With Nonverbal Learning Disabilities"**

Decked out in diamond earrings and a sterling silver gown, a Marilyn Monroe doll stands in a glass case on a counter at Meyer's Dolls Toys Hobbies in Livingston. But what Arline Shapiro prizes most in her store are the books stacked neatly in front of Marilyn — actually, multiple copies of a single book — by her favorite author.

That would be her grandson, Michael Murphy, who has written what he believes is the first book to address his learning disability from the perspective of the people living with it: "NLD From the Inside Out: Talking With Parents, Teachers and Teens About Growing Up With Nonverbal Learning Disabilities."

"My grandmother is my biggest booster," says Murphy, who says that Shapiro gives copies of the book to leaders of area schools and, occasionally, to parents of children she thinks might have NLD.

"No, she doesn't have a degree in neuropsychology," says Murphy, 29, who lives in Wayland, Mass. "But grandmas know a lot."

So does Murphy, and he has a couple of degrees to prove it: a bachelor's in psychology from Clark University and a master's in Jewish studies from Hebrew College,

"How could a grandmother not be proud?" Shapiro says.

Putting himself in a position to earn those degrees was not easy.

"He went to four colleges before he got his bachelor's," says his Millburn-raised mother, Gail Shapiro, who edited the book. "He flunked every single English course in high school," she says (though he was the rare NLD student who aced college calculus). "It was his third or fourth college, and he couldn't write a paper."

Among the schools Murphy attended was Landmark College in Vermont, which is highly acclaimed for students with learning disabilities. He spent a year and a half doing noncredit courses just to get up to speed, and it was not a great experience for him.

"NLD kids are a lot less mature," Shapiro says, adding that many are not ready for many of the more common strategies for learning-disabled students. "Since Michael was several years younger" than his chronological age, "this was like a very expensive summer camp."

Many of the strategies that work for language-based learning disabilities don't always benefit students with NLD.

"It was like, 'Let's take everything we ever heard that could help someone with learning disabilities and throw it all out at them,'" says Murphy, who plans to continue his education in Jewish studies or pursue a Ph.D in neuropsychology. "They had color-coded note-taking, mind-mapping, you name it. . . ."

"They were really good at teaching kids with a more typical LD, kids with dyslexia or ADD."

When he decided to enroll at Massachusetts Bay Community College, "everything changed," his mother says.

"It only takes one person at a time to redirect a life," says his stepfather, Gil Wolin, an aviation consultant also raised in Millburn, adding that Murphy's English professor "was that person for Mike at the time."

That freshman English class changed the way he thought about the subject, and he finally learned how to write an essay.

He discovered, for instance, that "it is not only legal, but encouraged" to hand in multiple drafts. "That never occurred to me," Murphy says.

"Michael thought you wrote a paper by sitting down and writing one perfect sentence followed by another perfect sentence," says Shapiro, a professional writer.

It was Shapiro who persuaded her son to write the book. He agreed — on the condition that she would be his editor. So what started as a 59-page college thesis ultimately became a book that fills an enormous void — a book written by and for people who know how difficult it is to grow up with NLD. "I was bullied like every single day in middle school," Murphy says. "It was always, 'If you tell, you're going to get beat up twice as bad the next day.' . . .  
"But you know what? Writing this book is the best revenge."

Like J.C., Murphy spent years in special education classes without a diagnosis, which he didn't receive until he was nearly 24.

Also like J.C., he has a prodigious memory. "Michael he didn't receive until he was nearly 24.

Also like J.C., he has a prodigious memory. "Michael knows everything about pop music — from Ricky Nelson to Ricky Martin to Lady Gaga," says his mother, Gail Shapiro, a professional writer who edited Murphy's book.

"He knows the lyrics to every '60s pop song ever written," says his stepfather, Gil Wolin.

He also knows a thing or two about social psychology — his book began at Clark University as a senior thesis on a minority population — and a little something about neurology.

He already knew that NLD was believed to be associated with the destruction of myelin, white matter in the brain's right hemisphere. But, he says, "I learned in my research that the prefrontal cortex was involved as well."

The encouraging news from Murphy's book is that, with the right support and interventions, people with NLD cope much better as they get older.

But finding the proper support is often a challenge, and everyday life for people with NLD — and their families — can be enormously stressful.

"As a parent," Shapiro says, "one has to go to that deep reservoir of calm and patience."

### **DRAMATIC IMPACT**

The struggle to fit in with their peers and the gaps in their knowledge, both academic and social, make NLD youngsters particularly vulnerable to bullying and teasing. Murphy says he was bullied daily in middle school, and J.C. recalls the humiliation of being mocked by the staff in his high school cafeteria for not knowing what cold cuts were.

"It can be devastating," Lewis says, "if no one in their world is knowledgeable about NLD."

That is all too often the case, given how frequently it goes undiagnosed. "The reason it's very hard to get a diagnosis is that it usually exists in conjunction with other disorders," says Sandra Newman, a learning consultant in the Hawthorne school district who diagnosed J.C. when she was in private practice in Fair Lawn in 2001.

As is the case with autism spectrum disorders, NLD is marked by deficits in social awareness or judgment. As a child who has not had appropriate interventions moves toward adulthood and expectations increase, social misperceptions and blunders occur more frequently and are more deeply felt.

The resulting feelings of low self-esteem, isolation and hopelessness put people with NLD at increased risk for depression, anxiety, drug addiction, alcohol abuse and suicide, experts say.

"These issues are complex and multifaceted," Newman says, "but even without a diagnosis, the symptoms can be recognized and treated."

And since NLD isn't in the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (better known as the DSM-IV), a child with NLD must be given another diagnosis anyway to receive special education services.

Children with NLD should be mainstreamed in the classroom with appropriate accommodations, modifications and learning strategies, experts say. Though they learn differently from their peers, they soak up information — especially rote material. And their strong verbal skills can be used as the primary means for acquiring additional skills. Their success depends on their ability to develop strategies to compensate for their weaknesses.

That takes a collaborative effort. In J.C.'s case, Newman worked with his teachers, and Lewis coached his parents in phone sessions.

"The idea is to teach people with NLD to read nonverbal cues in their own safe environments," Lewis says, "and get them out into the world to practice skills with people who understand and guide them." Because people with NLD have trouble "winging it," it's best not to place them in situations in which speed and adaptability are required. The world should be made as predictable as possible, with a clear set of rules and expectations.

### **'GRAYING OUT' THE WORLD**

In her earliest sessions with J.C.'s parents, Lewis emphasized the importance of providing verbal explanations for everything. "Words are their world," she says.

That world, however, tends to be black and white — and overpopulated with mind-numbing details.

"Our job is to enter their world and 'gray it out' — so they can become more flexible in their thinking," Lewis says. "People with NLD get caught up in details and have trouble seeing the big picture."

The inability to separate the essentials from the details affects interpersonal and social communication as well as academic performance. It is a point not lost on the families of people with NLD.

"Mike and I will be talking," Wolin says of his stepson, "and I'll say it's 4 o'clock, and he'll say, 'No, it's 4:03.' So often the drive for precision in the detail distracts you from the larger issue — that we're supposed to be somewhere at 4, and we're late."

Yet that extraordinary attention to detail enables people with NLD to excel in many areas, allowing them to pick up on what others miss. (J.C.'s encyclopedic knowledge of basketball and baseball and his strong verbal skills are pointing him toward a career in sportscasting.)

Helping this population reach its potential has become a mission for Fenton Turck of Cliffside Park, a financial planner who was diagnosed with NLD at 54. Turck, 61, is now working full time on a book and multimedia project to develop more effective ways of addressing the needs of people with NLD.

One of Turck's favorite metaphors is the baseball world. "When you're in slump, you don't look to yourself to figure out how to get out of it," he says. "You look to a coach, because you can't possibly see the intricacies of your swing or your timing."

"With NLD, the nuances of different issues ... the strengths and weaknesses ... are not visible externally or to oneself."

Consequently, Turck believes, there is no individualized coaching — at least on the scholastic level — to guide people.

So far, there are mostly individual solutions.

It is a point that Betsy Longendorfer of Ridgewood, an engineer who belonged to the same (now disbanded) NLD support group in Bergen County as Turck, has long emphasized to her 26-year-old NLD son, a journalist. "I always told Matt that everyone's body and mind has a user's manual," she says, "but the joke in life is that they don't tell you what it is ...

"You have to discover what works for you, and it's different for every single person."

J.C., who is attempting to navigate the world away from home for the first time, is still searching for that darn user's manual. But at least he has mastered the microwave in his dorm.

"Of course," he says, "my parents had to talk me through the steps of making macaroni and cheese."

That he can laugh about it is perhaps the most encouraging news of all.

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