DEEP DIVE

Autism in motion

BY **NICHOLETTE ZELIADT**

31 MAY 2017

video by Matthew Hopper

For 6-year-old Macey, lunchtime at school is not so much a break from reading and math as it is an hour rife with frustration.

Here's how Macey's mother, Victoria, describes Macey's typical lunch break: In her special-education classroom an hour north of San Francisco, Macey's classmates gather at a big square table, chattering away and snatching one another's food. Macey, meanwhile, is sequestered away at a small white table in a corner, facing a bookshelf. She grabs the handle of a spoon using the palm of her right hand, awkwardly scoops up rice and spills it onto her lap. She wants to be at the big table with her peers, but she sits with an aide away from the other children to minimize distractions while she eats. (Victoria requested that we use her and Macey's first names only, to protect their privacy.)

After lunch, the children spill out onto the playground. Macey, wearing a helmet, trails behind, holding her aide's hand. She can walk, but she often trips on uneven surfaces and falls over. She

tends to misjudge heights, and once pulled a muscle while climbing on playground equipment. When she was 3, she tripped and fell headfirst out of a sandbox, scraping her face, chipping one tooth and dislodging another.

Macey has little trouble moving around the house because it has few stairs and her mother never changes the layout of the rooms. Victoria's biggest concern is that Macey's movement troubles interfere with her social life.

Macey is naturally social: She likes interacting with adults but sometimes gets frustrated when they don't understand her. It's even more difficult with her peers. One afternoon last year, Macey watched her older brother and her cousins ride their bicycles in front of the house. When her brother took a break and laid his bicycle down on its side, Macey shuffled over and tried to climb on. "But there was no way," Victoria recalls. "She's wobbly, and I was afraid she would fall off and hurt herself." Victoria gently led her daughter away from the bicycle. Tears began to stream down Macey's face as she shouted, "I want bike!"

Macey will probably have these motor problems her entire life. They are a characteristic feature of her condition: She has an extra copy of a small stretch of DNA on chromosome 15, which causes a condition called **dup15q syndrome**. Like most children with the syndrome, Macey also has autism.

About 80 percent of people with autism **have some sort of movement problem**, ranging from clumsiness or a mechanical style of walking to more profound difficulties like Macey's. "It is very, very common for children with autism to have clear impairments in their motor control," says **Stewart Mostofsky**, director of the Center for Neurodevelopmental and Imaging Research at the Kennedy Krieger Institute in Baltimore, Maryland.

Despite their prevalence, movement problems are not considered a core feature of autism — that is, they are not required for an autism diagnosis. And **they are understudied** compared with the social difficulties and **repetitive behaviors** that define the condition. "For many years, it has been ignored as a challenge that children with autism experience," says **Nicole Rinehart**, director of the Deakin Child Study Centre at Deakin University in Melbourne, Australia.

A few scientists, including Rinehart and Mostofsky, are precisely measuring the movements of children like Macey to find brain features that might underlie motor difficulties. Because motor problems often emerge in infancy, well before other features of autism, some researchers are pursuing a provocative idea: Movement problems might be one source of the social difficulties in people with autism.

The theory goes like this: Children who have trouble exploring their environments miss out on opportunities for social interactions, making it difficult for them to learn communication and social skills. Later on in childhood, their clumsiness prevents them from participating in group activities, worsening their social problems. This is a controversial idea, but if true, it means that therapies that

teach people with autism how to move more fluently could also help them interact with others.

Movers and shakers:

In 1943, Leo Kanner **chronicled the medical histories** of the 11 children who were the first to be diagnosed with autism. Some of the parents told him that their children had learned to walk late. And that when the parents reached for their babies to pick them up, the children did not raise their arms or tuck their legs — as babies typically do when they are picked up. A year later, the Austrian pediatrician Hans Asperger also described odd gestures and posture in four boys with autism. He described one boy, Fritz, as having “no mastery over his body” and “atrocious” handwriting, according to an English translation of his written account. About another boy Asperger wrote, “He could not possibly catch a ball, however easy one tried to make it for him.”

In the ensuing decades, scientists focused on other, more consistent and troubling, features of autism, such as social problems and difficulties with communication. But in the 1980s, standardized tests of motor skills began to confirm these initial observations.

The movement problems vary from person to person, but most people with autism have some difficulty coordinating their movements — such as turning their head while reaching for an object — as well as trouble with balance. Perhaps as a result, they also have trouble with many everyday tasks, from fine-motor tasks such as buttoning a shirt to gross-motor skills such as running, jumping or catching a ball.

Strolling style: As Liam walks, video cameras track the movement of his limbs and torso in three dimensions. Photo by Matthew Hopper

The research available so far suggests that these difficulties **begin early in life**. Home-video analyses reveal that children later diagnosed with autism tend to have trouble **turning over and sitting up as infants**, and are **late in learning to crawl**. Their movements are also often asymmetric: When walking or crawling, the limbs on one side of the body **do not mirror** those on the opposite side. Parents echo these observations: They tell doctors that their child lagged behind their typical peers in learning to walk, or has trouble learning complex, coordinated movements, such as pedaling a tricycle. “If you ask any parent of a child with autism, you get near-universal agreement that this is an issue,” Mostofsky says.

Victoria knew something wasn’t quite right when Macey didn’t learn to walk until she was 2. Even after Macey began walking, she remained unsteady. “She looked like a drunken sailor,” Victoria says.

It is unclear why children with autism have these problems, but emerging research is beginning to provide some clues. An unpublished study of more than 2,400 children with autism suggests that, compared with other children on the spectrum, those who carry certain rare mutations strongly linked to autism **are more likely to have motor problems**. This suggests that some motor problems in people with autism have genetic underpinnings.

Others researchers are using computational methods that reveal which parts of the body are not moving properly during certain tasks. When people with autism perform the tasks, they have characteristic difficulties that suggest the brain areas or circuits affected — information researchers can use to identify exactly what goes awry.

“For many years, motor problems have been ignored as a challenge that children with autism experience.” Nicole Rinehart

Busy bodies:

Inside a small, dark lab in Melbourne on a December morning, Rinehart watches as a girl named Catherine, then 12, walks the entire length of a brown floor mat that spans the room diagonally.

Pressure sensors in the mat detect the girl's footsteps. Wires connect the mat to a computer in the corner, which collects data in real time and calculates Catherine's walking speed, her stride length, and the distance between her feet. Rinehart uses the automated system to compare the gait of children who have autism with that of their typical peers. (Catherine is Rinehart's daughter, and does not have autism; Rinehart conscripted her to demonstrate the technology.)

The length and width of Catherine's stride are highly consistent. By contrast, Rinehart says, children with autism tend to have a wide stance, and their stride length and width vary from step to step. These patterns may explain why some people with autism seem to have an unusual walking style — even if it's difficult to pinpoint exactly what's odd about their movements.

Rinehart's colleague, **Jennifer McGinley**, guides Catherine through a series of increasingly challenging tasks. The girl walks smoothly along a narrow black line on the mat as if balancing on a tightrope, placing the heel of her lifted foot directly in front of the planted one with each step. Children with autism might instead stumble off of the line or walk along it without lining up their feet heel to toe as instructed — a classic sign of problems in the cerebellum, **a brain region that coordinates movement**.

Catherine is then asked to walk as fast as she can while naming types of pets or items of furniture typically found in a home. This test reveals whether multitasking can cause difficulties to emerge. "When you look at a playground, you don't often see kids walking along slowly and silently by themselves," McGinley says. "So we need to look at how they cope when they're doing other things as well." On this task, Catherine walks slightly more slowly than she did when she was not required to answer questions. People with autism walk even more slowly or are wobblier than usual, which suggests that problems with attention may also factor into their movement challenges.

To provide a more complete picture of gait, Rinehart's team uses a 3-D tracking system, housed at the nearby **Kingston Centre** clinic, to measure the movement of the limbs and torso. Researcher **Anna Murphy** demonstrates how it works with her 7-year-old son, Liam, who does not have autism. "Mom's going to turn me into a skeleton," Liam says as his mother peels off his shirt and attaches small reflective markers to his bare shoulders, elbows, chest and back, as well as his hips, thighs, knees, calves and ankles. Murphy slides a stretchy headband with four additional sensors around his forehead, and places a smaller band with two sensors around each of his wrists.

As Liam walks along a black strip of plastic affixed to the floor, a series of eight infrared cameras connected to a computer near the back of the room track the movement of the markers. Liam's body appears as a neon-green skeleton strutting across the computer screen. The system measures parameters such as the angle of the torso and that of the pelvis, as well as the overall degree of movement of his upper body. Murphy's unpublished data indicate that the upper bodies of people with autism tend to tilt forward as they walk, and that they have more bounce in their step than their typical peers do. These findings align with the results of the two-dimensional footstep

analysis. “If you’ve got more movement in your trunk, you tend to be more unstable at the bottom, so you account for that by widening the step,” Murphy says.

From these types of studies, Rinehart and her colleagues ultimately hope to be able to identify movement patterns that distinguish autism from other conditions. The team is recruiting children with autism as young as 2 years old to see if the same patterns of altered gait turn up in toddlers with the condition.

“What this group has done is remarkable,” says **Shafali Jeste**, associate professor of psychiatry and neurology at the University of California, Los Angeles. “Many of us see that children with autism have motor impairments, but it has remained a clinical observation; they’re taking that clinical observation and turning into something measureable and quantifiable.”

Moving forward:

Babies typically learn to talk in large part by moving their bodies first — or so one leading theory goes. When babies reach out to their parents or bring them a toy, the parents may respond verbally, which helps the babies learn to communicate. Infants who explore less than usual “are not experiencing words in the same way,” says **Anjana Bhat**, associate professor of physical therapy at the University of Delaware in Newark.

In babies with autism, motor problems become apparent early — well before social and communication difficulties, which typically aren’t noticeable until after a child’s first birthday. These observations come from studies of so-called ‘**baby sibs**,’ the younger siblings of children with autism, who are at **increased risk of the condition**. As early as 3 to 6 months of age, infants later diagnosed with autism show **delays in rolling over** and holding up their heads. They also don’t reach for things around them as often as typical babies do, and have trouble **grasping and manipulating toys**.

Even though the children may eventually acquire these abilities, “it’s not irrelevant that a baby has these postural control and grasping challenges,” says **Rebecca Landa**, director of the Center for Autism and Related Disorders at the Kennedy Krieger Institute, who has led some of the studies. Delays or disruptions in learning to stand and walk limit a child’s ability to explore her surroundings and interact with others. “These simple little things that might seem inconsequential can add up over time, and put the child at risk for other delays, like in language or social interaction,” Landa says.

A few studies have found that baby sibs with motor delays in infancy have trouble **learning to speak and understand words**. The severity of motor difficulties also predicts the **extent of their social problems**. Bhat and others say that movement problems in infancy have cascading effects on communication and social development.

But not everyone agrees with this hypothesis. Motor problems may develop before social ones, but that doesn't mean they are causal, argues Mostofsky: "I don't think that argument holds up to scrutiny." In his view, movement problems only appear to precede social difficulties because motor skills develop earlier than social skills. "Motor development is much more prominent in the first year of life," he says. At that early stage, "you might not detect signs in social communicative development, because there isn't much at that point to detect."

Instead, Mostofsky says, motor and social deficits are both manifestations of a deeper problem: **faulty connections** between certain brain regions. The disrupted connections make it difficult for people with autism to **incorporate visual information** when they plan movements. Being able to do this is key to social interactions — for example, making appropriate gestures and facial expressions in response to another person's words or actions.

In support of this idea, his team reported in 2009 that when children with autism learn to control a robotic arm, they **rely primarily on proprioception** — that is, sensations gleaned from their own muscles — rather than on visual information, as typically developing children do. The less the children depend on visual information, the more severe their problems with social skills. He also reported in 2015 that children with autism have more **difficulty catching a ball** than do children with attention deficit hyperactivity disorder. "This is a task where you have a projectile coming at you, and you have to quickly adjust your movements based on that visual input," he says.

Mostofsky also has data from imaging studies that support his theory: Typical children with the most synchronization between visual and motor brain regions tend to have the best imitation skills. These regions are often **out of sync** in children with autism; and those least in sync have the **most severe autism features**.

"If you ask any parent of a child with autism, you get near-universal agreement that this is an issue." Stewart Mostofsky

Field day:

Even researchers such as Mostofsky who don't generally believe that movement problems disrupt social skills say that **treatments that improve motor skills** may help people with the condition socially. **Several small studies** hint that **movement-based therapies** boost social skills, communication abilities, attention and behavior.

Parents of children with autism are gravitating toward programs that promise to teach physical skills. For example, a summer program to teach children with autism how to ride a bicycle was filled to capacity in a matter of days, says the program's leader **Megan MacDonald**, assistant professor

at Oregon State University in Corvallis. “It clearly indicated to us a need for opportunities like this,” she says.

Other researchers have also launched similar programs. Mostofsky’s team is developing a video game that helps children with autism learn to dance by imitating an avatar, with the goal of strengthening connections between the visual and motor areas of their brain. Mostofsky predicts that the game will boost both motor abilities and social skills. He is scanning the brains of the children with autism before and after they play the video game to assess the results.

Play time: Team sports, such as Australian-rules football, might ease social difficulties in children with autism. Courtesy of AllPlay

A few programs more overtly combine both physical and social training. Shafali Jeste’s **ACEing Autism** program, which teaches basic tennis skills, launched in 2008. The coaches teach children

with autism social cues, including how to follow and interpret a partner's movements to predict his next move. Jeste is launching a pilot study, intended to include at least 20 children with autism, that will use standardized tests and other quantitative measurements to assess whether the program improves children's motor skills, eye contact and other behaviors.

Along similar lines, Rinehart and her colleagues have partnered with the Australian Football League to create **AllPlay**, a program that teaches children with autism or other developmental conditions to play the sport. The coaches modify activities and drills: A coach may position the child closer to the goal line or use a lighter football, for example. The program naturally combines physical education with social training, as parents and children have the opportunity to meet new people, play in groups, learn to cope with crowds and prepare for physical contact with others. Rinehart's team plans to measure the walking patterns and social skills of children with autism before and after the program.

As much as Victoria would like to sign Macey up for something like this, her daughter is too young. "She's 6, but she has the mentality of a 3-year-old," Victoria says. Until three years ago, Macey attended a Sunday school program for toddlers, where she could interact with children of her emotional or intellectual age. But the church decided that Macey is too big to play with children who are years younger than her. "The other parents were afraid that she was going to fall over and hurt them or something," Victoria says.

For now, she and her husband are doing the best they can on their own. They are thinking about purchasing an adaptive bike, a three-wheeled contraption that does not require balance. It would keep Macey safe — and still allow her to play with other children.