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# WHY M.I.N.D. MATTERS

How a group of determined parents did the impossible and helped form one of the leading autism research facilities in the country. by **Gary Delsohn**

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Chuck Gardner will never forget what his good friend Rick Rollens told him after Gardner asked for advice about how to approach officials at the University of California, Davis, with his dream of creating a world-class research and treatment center for autism.

"You're wasting your time," Rollens said during that 1996 conversation. "It's never going to happen. I've worked with the UC system, and it will never happen in our lifetime. It takes them 10 years to decide whether to build a parking garage."

Both men — Gardner, who is a business owner in Sacramento, and Rollens, then secretary of the California Senate — had young sons who have the often-debilitating brain malady known as autism. The two men and their wives had been everywhere searching for help. They were long past desperate for something, anything, that could provide hope or relief.

It's a good thing Gardner didn't take Rollens' pessimism to heart. He says now that he didn't know better at the time. That four years of sleepless nights while he and his wife, Sarah, kept constant vigil over their son, Chas, a handsome boy with no verbal skills but an uncanny ability to hurt himself and turn their household upside down, made him crazy enough to think even the impossible was possible.

With the help of another friend, Gardner got his meeting with officials at the UC Davis Medical Center, which is on the old State Fair grounds in Sacramento. Even though they established some ground rules that seemed impossible to meet — like come see us again when you've raised \$5 million in private funds — Gardner remained undeterred. As a result, the Medical Center campus today boasts what experts say is the leading autism research facility in the nation, if not the world.

It's housed in a gorgeous 100,000-square-foot, state-of-the-art building that cost \$42 million to build and is designed so thoughtfully that *The Wall Street Journal* wrote a separate story about its architecture. It ran under the sub headline "Can a Building Help Cure a Disease?" Officially open since 2003, just seven years after Gardner and Rollens first talked about the pipe dream of an idea, the center boasts a full-time staff of 260 and has already conducted several groundbreaking research projects. The center's most recent undertaking: an ambitious autism study that is expected to radically change how the disease is diagnosed and treated. All because

a small group of parents demanded action and took matters into their own hands when they weren't satisfied with what they were getting.

The story of how Gardner, Rollens, and a small cadre of extraordinarily frustrated but determined Sacramento parents achieved their quixotic goal is almost as dramatic as the groundbreaking research being conducted at the facility. It's called the M.I.N.D. Institute, for Medical Investigation of Neurodevelopmental Disorders. Even the federal government says it represents the best hope anywhere for a cure and answers about how to prevent and treat this perplexing brain disorder. It wasn't that long ago, after all, that autism was believed to be caused by so-called refrigerator mothers, too cold to properly nurture and develop their children. The common advice from doctors to parents was find a place to institutionalize your child. You'll never reach him.

Now we at least know it's a brain malady, that some children are born with it and others contract it somehow in their first few years of life, maybe by exposure to infant vaccines preserved with the mercury-based substance known as thimerosal. And there are treatments that help. Chas Gardner goes to a school for kids with autism that his father and two partners built and co-own. He's learning independent living skills, such as how to order food at McDonald's and motion toward things he wants. Just a few years ago, this was a disease believed to affect one in 10,000 kids. Now, according to the federal Centers for Disease Control and Prevention, it afflicts as many as one in 166 children who have some degree of autism spectrum disorder. The CDC estimates that if 4 million children are born in the United States each year, about 24,000 will be diagnosed with autism. Because most of the known patients with autism are under the age of 18, many experts say this is a medical and social time bomb as these kids get older and become far more dependent on society at large to care for them.

"I would say that the M.I.N.D. Institute is really the hope for people with autism," Dr. Thomas Insel, director of the National Institute of Mental Health, said in a recent interview. "What parents need most of all is hope for a breakthrough, and this is the place in the country that is totally committed to finding that breakthrough. It's so impressive to learn that families got this facility started because they were so intent on trying to solve the problem with

more research. They've created a place that is really a focal point of scientific effort, almost a Manhattan Project, to try to understand the reason for this disease, how to prevent it, and how to treat it better."

Gardner, Rollens, and the four other men known as the center's "Founding Fathers" know work at the M.I.N.D. Institute may come too late to make a dramatic impact on the lives of their sons, now young teenagers. One founder, trucking company owner Steve T. Beneto, has a son with autism in his 40s who has been living away from home in an around-the-clock care center for years. But the families remain fully engaged in the institute's work, mission, and future. Gardner is running the center's new fund-raising drive.

"You never know if something is going to come out of it that will help Chas," Sarah Gardner, a Sacramento television news anchorwoman and Chuck's wife, says with a sigh. "But we have so many friends who have kids with autism. No child or family should suffer like this. The reality is that every day that passes, Chas gets further away from a cure. But we're going to continue to be unrealistic and think there's something out there that will help him. We're prepared to take that hope to our grave if that's how it goes."

The project started with Chuck Gardner's frustration and his ability to network with other fathers who saw their families strain and creak under the intense pressure of having a child with autism. For some reason scientists don't yet understand, autism is far more prevalent in boys than girls. Boys have it more than girls by a ratio of four-to-one.

For the most part, the moms of the boys were home dealing with their tantrums, trying to get them to eat, learn, sit still, and not harm themselves or their siblings while the dads were out scouring for help. "We're dads," Rollens has said many times. "When something goes wrong, we're supposed to try and fix things."

Gardner was stunned to learn that so-called experts at one clinic where autism was treated didn't know what scientists at another center were working on. They often didn't even know about studies and facts Gardner and some of his friends who have children with autism had found on their own. Chas had been diagnosed at about 2 and was 4 when Gardner had his meeting with the university. At the time, he and his wife were very frustrated.

Even as a baby, Chas hated to be held. He didn't talk or look directly at someone

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who was talking to him. Almost anything could set off wild, often violent tantrums. A few years ago, while Chuck was sitting on the fireplace mantel watching Chas, Chuck turned away and Chas stuck his leg into the burning fire. His pajamas ignited, and he suffered second-degree burns. When he eats, Chas likes to cram whatever he has in front of him into his mouth all at once because he craves the sensation of a full mouth, making his parents experts on the Heimlich maneuver. When his younger sister, Ginny, wants to have a friend over to play, the logistics can be nearly impossible.

"People say to us all the time, 'Isn't it time you found a place for him and had him institutionalized?'" Sarah says. "That's all well and good. You try to pack his bags and put his favorite things in there."

At a conference he attended, Chuck mentioned to Dr. Louis Vismara, a prominent (and now retired) Sacramento cardiologist whose now-13-year-old son Mark has autism, what the university officials had told him about the need to raise \$5 million to have even a prayer of getting anything serious started at UC. Even then, all they promised was a couple of endowed professor's chairs at the medical school, nothing like a full-blown center devoted primarily to autism.

Vismara had been practicing medicine in Sacramento for years, and he had quite a few wealthy patients. Among them was Angelo Tsakopoulos, a major California developer. Tsakopoulos, who still has a hard time with his own dyslexia, couldn't get on board fast enough.

"The logic that we spend something like \$10 billion to \$12 billion a year to take care of people with autism and only \$50 million a year to do research is mind-boggling to me," Tsakopoulos says. "I told Lou at the time it's like having a building with a roof that is leaking and you spend a ton of money on buckets when you need to fix the roof. To really learn about this disease and why it affects people as it does, we need to do the research."

Tsakopoulos kicked in \$500,000. So did Beneto. Vismara put in \$250,000. Another Vismara patient, Claire Massey, and her family put in \$1 million at the start and recently gave the institute another \$1 million. Rollens used his influence in the Legislature to get a bill passed appropriating \$2 million toward the establishment of a research center then called Project Hope. In 1999, then-Governor Gray Davis, who was taken with the story of Rollens' struggles to find relief for his son, signed

legislation appropriating \$40 million to help build the facility. The Medical Center donated several acres of land and added more than \$20 million to the pot. In 2003, the M.I.N.D. Institute, which also includes a 27,000-square-foot lab that is the envy of other departments at the Medical Center, was formally christened. It has an annual budget of \$18.9 million, which includes \$3.8 million from the state.

In addition to how it was created, the center is unique because it freely mixes clinical and research space under one roof with open, flowing design. The center has one main entrance where doctors, psychologists, researchers, and administrators all enter before going off to their individual work stations. Wide stairways invite conversation. The open layout allows occupants to see one another. The soothing earth tones and dramatic artwork commissioned from artists with autism make the center an inviting place. It's a dramatic departure from the dingy, private clinics most of these parents had been accustomed to. Parents desperate for hope can literally see the promise of science being applied to their own children. Because it is part of the UC Davis Health System, which also has one of the leading veterinary medicine schools in the country, the M.I.N.D. Institute, which has more than 3,000 clinical research visits each year, is able to take advantage of the university's vast array of resources. On one winter morning when a reporter was being shown around, researchers were in the lab dissecting monkey brains to learn what goes into a primate's memory system during development.

"It's kind of exciting for us because of the phenomenon of infantile amnesia," Jeff Bennett, a lab manager, says as he sorts through some tissue slides. "We think there could be an interesting change that happens during development that can help shed light on some of these disorders."

The most ambitious project undertaken at the M.I.N.D. Institute and arguably the most far-reaching autism study done anywhere is what's known as the Autism Phenome Project. Institute officials describe it as a "longitudinal study that aims to distinguish among different subgroups (or phenotypes) of autism and will link these subgroups with distinct patterns of behavior and biological changes. Assessments include family history, environmental exposures, genomics, behavior, brain structure and function, immunology, as well as protein profiles." The aim of the project is to

finally differentiate between the different types of autism and how they are caused so diagnosis and treatment can be tailored to each individual.

"At the moment, any treatment that gets used — it gets used for all kids with autism," says David G. Amaral, a professor of psychiatry and behavioral sciences at the UC Davis School of Medicine and research director at the M.I.N.D. Institute. "Some kids respond well and some don't, but we don't know why. This is critical because when you have a developing child there is a window of opportunity when treatment is most valuable. You don't want to guess. You want to get the best possible treatment at the best possible time."

That particular window has likely closed for Chas, Mark Vismara, and Russell Rollens, who was on the cover of *Newsweek* in July 2000 for an article on what the magazine called "Mindblindness," another name for the disorder. Chas' parents admit they try not to let their minds wander to thoughts about who'll care for Chas when they're not around. They're too busy with the day-to-day.

"We can cry and worry about the future when we're older," Sarah Gardner says. "We don't allow ourselves to ever go over to any kind of dark side and just worry. We don't have the time or luxury for that, and once you do, you may never find a way out. One thing I do know. Chas is not going to pass through this world without having an impact. He may not be the pro baseball player Chuck dreamed of when he was born, but because of his involvement and participation in this research, he's going to have an impact. We will find a cure, and Chas will have played a role in that." ♡

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Gary Delsohn was a reporter for the *Sacramento Bee* for 16 years.

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