

Locked-Out Syndrome

An innovative art program for the severely disabled can't find a home in Chicago.

By Deanna Isaacs

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Fifteen years ago, Tim Lefens accepted an invitation to make a guest artist appearance at the Matheny School, a New Jersey residential facility for kids with disabilities. Lefens, a painter, wasn't prepared for what he found there. The kids, mostly quadriplegic and unable to speak, faced extreme physical challenges. Here's his description of the first of three students who showed up for his lecture, from *Flying Colors*, his 2002 book about the experience:

“In the center of the room sits a—a something, a person, his head held upright by a network of stainless steel wires that run like spokes from a metallic headband to aluminum armatures bolted to the back of the wheelchair. His underdeveloped body sits rigid, symmetrical as the chrome wheelchair. His brittle stick arms are strapped to the vinyl-padded armrests, his hands dangling off the ends, the fingers twisted, bent backward, welded into knots. From the immobilized head, his eyes meet mine. A burst of voltage passes from him, through his eyes to me.”

The kids were captives, serving life sentences in their own dysfunctional bodies. But what disturbed Lefens even more was the disconnect between the glimpse he got of the fire inside them and what he'd seen of their existence at the school—strapped into wheelchairs and parked in front of the TV watching *Barney*, for example. Again, from *Flying Colors*: “It is difficult to imagine anything harder than the restrictions they endure. But there is something worse—if they, as it appeared to me, are as alive as you or me and they are being treated like idiots.”

Shaken by his brief visit, Lefens offered to lead a weekly art class at the school. Though he'd never done any teaching, he was determined to find a way for these kids to express themselves.

Rejecting the hand-on-hand method that was standard—and that results in art created by the teacher, not the student, he says—Lefens began with a wheelchair technique. He taped canvases to the floor, lathered them in paint, covered the wet paint with a sheet of plastic, and then let the kids roll across, turning the wheels into a tool. When they quickly exhausted the possibilities of that cumbersome approach, he came up with a much better one. Recognizing that his students needed equipment that would be fast and precise, Lefens jury-rigged a gizmo similar to the face guard worn by football players, and attached a laser pointer to the front of it, at about nose height. Sit before a canvas wearing this contraption and your slightest head movement will direct the laser beam. Add an assistant (a “tracker” in Lefens's lingo) who follows the beam in whatever pattern it describes, using colors and tools chosen by the artist, and you can wind up with paintings by kids who not only can't lift a brush but probably haven't executed a plan of their own in their entire lives.



A Splash of Pink by Neffertiti Lancaster and an untitled work by Vicky Runcowicz; Tim Lefens



Lefens says he had to battle the Matheny administration for the entire seven years he spent as a part-time teacher there. But his class, which served a small number of the school's residents, became a high-profile success. The students turned out striking abstract paintings that were shown—and sold—in galleries in New Jersey and New York, bringing them recognition, respect, and their first earned income.

The Matheny program was the subject of a feature shown on the CBS Evening News, and, Lefens notes, spurred a multimillion-dollar capital campaign that eventually built the school an art center. But when he wanted to expand beyond Matheny, to share his techniques with other organizations so that more people could benefit from them, Lefens says, he ran into opposition from the president and their long-standing differences came to a head.

He quit his job at Matheny in 1999, and wrote the story of his wheelchair warriors and their minirevolution. Published by Beacon Press, *Flying Colors* became a Reader's Digest choice for best nonfiction. Now Lefens works through a small nonprofit organization—Artistic Realization Technologies or A.R.T.—and has an anchor program at Princeton University. He's also joined the ranks of the disabled, in a way that makes creating his own art especially difficult: afflicted with retinitis pigmentosa, Lefens is now legally blind.

For a tiny organization (2006 budget just over \$200,000), A.R.T. boasts a knockout board of directors. Members have included John McPhee, Willem Dafoe, Roy Lichtenstein's son David, and Neil Young. Though Lefens says he still has to hustle to raise money, funders like the Christopher and Dana Reeve Foundation are backing him, and A.R.T. has programs running in about 20 locations around the country.

His references are raves. Gail Lesko, a manager for Manasota ARC, a day program in Bradenton, Florida, says they've had an A.R.T. program for a year with 12 artists and four trackers, and "it's one of the best things we ever did." Lesko says paintings have sold for as much as \$1,500 (split 60/40 between the institution and the artist), and that the proceeds, along with grant money, cover the cost of the program. "But," she says, "the most important thing is what the artists are getting out of it."

The T.K. Martin Center for Technology and Disability at Mississippi State University, Starkville, has had a program for three years, and case manager Judy Duncan agrees that it's had a tremendous impact on people "who do not make a single choice in their lives." Says Duncan, "It's one of the most powerful things I've ever seen."

A.R.T. is launching programs in a half dozen east coast locations this year, but Lefens has been frustrated in his attempts to bring one to Chicago. He says even though he can deliver funding there are no takers among the organizations here. He's been turned down by the Misericordia support facility (they'd like to see a demonstration first, they told me), the Walter S. Christopher School (which says they don't currently have any suitable students), Access Living (which doesn't offer art classes), and the Rehabilitation Institute (a hospital, and therefore not appropriate for an ongoing art program, they say). The only glimmer so far: the Rehab Institute might host a demonstration in the fall.

Lefens says demonstrations are dangerous: people watch for half an hour and think they've got it. But if trackers aren't properly trained, the program gets botched. He'll do a demo here if he has to, he says, but he's puzzled by the resistance. "There seems to be . . . a sort of fiefdom thing going on," he observed in a recent e-mail. "Free money, free training, all my secrets of the breakthrough, better more prestigious vetting than any group they've ever worked with and we get the straightarm . . . I simply don't get it."

The potential artists are here, he's sure of that. How can it be, he wonders, that no one in Chicago wants to set them free? **Я**