

NEWS

# Autism's history holds lessons for today's researchers

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The past six months saw the release of two bestselling books about autism: Steve Silberman's "**Neurotribes**," and John Donvan and Caren Zucker's "**In a Different Key**."

Both books chronicle the oftentimes dark history of autism while expressing hope for a better future for people with the condition. They focus on the good work of people — strong-willed parents and devoted advocates — who transformed a once-shameful diagnosis into a widely accepted condition. But they also highlight several missteps by scientists that derailed research and the lives of many people on the spectrum.

This history offers lessons for today's scientists, ranging from the importance of purging presumptions about autism to the acute need for services that help people, especially adults, with the condition.

The books take the reader back to the infancy of autism research. In the late 1940s, psychiatrists declared that they had found autism's cause: cold parents — particularly mothers — who did not love their children enough. **Leo Kanner**, one of the first psychiatrists to study the condition, abandoned his own theory that autism was innate in favor of what would later be called the '**refrigerator mother**' hypothesis.

"If Kanner had really stuck to his guns and gone with his instincts, it's possible the whole refrigerator mother theory never would have evolved the way it did," Donvan says.

Kanner later recanted the refrigerator mother theory, but for the next two decades, many psychiatrists focused on treating what they believed were defective mothers and fathers. Research exploring other explanations for the condition stagnated.

Having a scientific orthodoxy can be a positive thing, but it can cause severe damage if it turns out

to be inaccurate, Donovan says. “The history of autism has shown that, time and time again — particularly in the early days — researchers failed to examine their own assumptions and biases.”

## Biased beliefs:

Flawed assumptions also invade researchers’ attitudes toward people with autism, according to Silberman. He says scientists long viewed people with autism as less than human, rationalizing a range of ‘treatments’ that were more akin to torture than therapy, including electric shocks and physical abuse such as hitting. Although contemporary practitioners have largely abandoned these methods, some continue to use punishment as a means of modifying behavior, he says.

“The first question that should be asked in any research project is, ‘Would you do this to a non-autistic person?’” he says, noting that asking adults with autism for their input is a crucial second step. “Autistic people should be seen as valuable collaborators in your work, rather than as passive subjects.”

Many researchers working in the field today are motivated by a deep desire to help people with autism, Donovan says. But scientists should still ask themselves, “Is there anything I’m doing now that I may regret 20 years from now?”

Some of the researchers who tested electroshock therapy or hallucinogenic drugs in children with autism back in the 1950s and '60s did so with the best of intentions, Donovan says. “In light of modern mores and best practices, those choices look bad today,” he says. “But that does not mean those researchers were motivated by cruelty or sadism.”

## Research revamp:

The 1990s saw a sea change in awareness of autism. People previously diagnosed with childhood schizophrenia or minimal brain damage were recognized as having autism all along. This new awareness sparked the notion of an ‘autism epidemic,’ which drew an influx of research dollars into a once underfunded and overlooked field. But unfortunately, little of this money went toward helping people with autism.

It went largely to uncovering autism’s cause, giving scientists insight into the workings of the brain. It also generated leads for drug targets. But for people with autism and their families, “the tangible benefits remain elusive,” Silberman says.

Researchers know “astonishingly little” about **the lives of adults with autism**, he adds, including **how many of them there are**, how other conditions associated with autism **affect their lives** and how best to translate their abilities into **meaningful employment**. Likewise, little research focuses on how autism **manifests itself in women**, or on determining the prevalence of autism in **minority communities** with limited access to diagnostic services.

There is also little research into better drugs for controlling seizures — one of the **leading causes of death** among people with autism.

“These are not questions that can be answered by sequencing another set of genomes of people from multiplex families,” Silberman says. “That kind of work is still very much worth doing, but if we’re only doing that kind of long-range research, we’re not really meeting our responsibility as a society to help the autistic people who are all around us lead happier, healthier, more fulfilling and more secure lives.”

## Intervention caution:

For those who are investigating treatments and services for people with autism, Zucker and Donovan warn that the work carries great responsibility. Parents are desperate for guidance about how to help their children, they say — especially in light of the emphasis **put on early intervention**. As past examples ranging from **vitamins** to **hugging therapy** have shown, families will rush to adopt new methods that are prematurely presented as solutions.

“Researchers need to be very, very careful in how they present their findings, so as not to set off hope for a quick, silver-bullet-type solution,” says Donovan.

How researchers talk to the press can **shape the public reaction** to research. In 1987, for example, *The New York Times* reported on the work of Ivar Lovaas, a clinical psychologist and pioneer in applied behavior analysis. The story, titled “**Researcher Reports Progress Against Autism**,” described children who were “transformed” into “apparently normal children.”

Although Lovaas never used the word ‘cure’ when talking to the *Times*, the story implied as much. The fact that his research was preliminary was largely overlooked. Parents frantically flew their children to his lab at the University of California, Los Angeles, even as he hopelessly tried to correct the false headlines.

Today’s scientists should take great care when describing their work and **strive to communicate their findings** in terms non-experts can understand, Donovan says. “Researchers need to understand that there’s a public that is hanging on their every word.”

**Editor's note:** *This story has been modified to acknowledge the fact that Kanner eventually recanted the refrigerator mother theory.*