

Discovering Autism: Homing in on the right label

December 19 2011, By Alan Zarembo

When autism researchers arrived at Norristown State Hospital near Philadelphia a few years ago, they found a 63-year-old man who rambled on about Elvis Presley, compulsively rocked in his chair and patted the corridor walls.

Ben Perrick, a resident of the psychiatric institution for most of his life, displayed what the University of Pennsylvania researchers considered classic symptoms of [autism](#). His chart, however, said he was schizophrenic and mentally retarded.

Delving into the file, the researchers learned that as a 10-year-old, Perrick had seen Dr. Leo Kanner, the psychiatrist who discovered autism. In his notes from 1954, Kanner described Perrick as "a child who is self centered, withdrawn, and unable to relate to other people," and recommended that he be committed.

Later, other doctors relabeled Perrick. The [autism diagnosis](#) was forgotten.

The researchers found 13 other patients with unrecognized autism in the Norristown hospital - about 10 percent of the residents they evaluated. It was a sign of how medical standards and [social attitudes](#) toward the disorder have shifted.

Over the last two decades, estimates of the autism rate in U.S. children have climbed twentyfold. Many scientists believe the increase has been

driven largely by an expanded definition of the disorder and more vigorous efforts to identify it.

Scientists are just beginning to find cases that were overlooked or called something else in an earlier era. If their research shows that autism has always been present at roughly the same rate as today, it could ease worries that an epidemic is on the loose.

By looking into the past, scientists also hope to deepen their understanding of how autism unfolds over a lifetime.

What happened to all the people who never got diagnosed? Where are they?

Like Perrick, who died in 2009, some spent their lives in institutions. Mental hospitals have largely been emptied over the last four decades, but the remaining population probably includes about 5,000 people with undiagnosed autism, said David Mandell, a psychiatric epidemiologist who led the Norristown study.

Many more are thought to be in prisons, homeless shelters and wherever else social misfits are clustered.

But evidence suggests the vast majority are not segregated from society - they are hiding in plain sight. Most will probably never be identified, but a picture of their lives is starting to emerge from those who have been.

They live in households, sometimes alone, sometimes with the support of their parents, sometimes even with spouses. Many were bullied as children and still struggle to connect with others. Some managed to find jobs that fit their strengths and partners who understand them.

If modern estimates of autism rates apply to past generations, about 2

million U.S. adults have various forms of it - and society has long absorbed the emotional and financial toll, mostly without realizing it.

The search for the missing millions is just beginning.

The only study to look for autistic adults in a national population was conducted in Britain and published in 2009. Investigators interviewed 7,461 adults selected as a representative sample of the country and conducted 618 intensive evaluations.

The conclusion: 1 percent of people living in British households had some form of autism, roughly the same rate that the U.S. Centers for Disease Control and Prevention estimates for children in America today.

The British study found it didn't matter whether the adults were in their 20s or their 80s. The rate of autism was the same for both groups.

"That would seem to imply the incidence has not changed very much," said Dr. Terry Brugha, a professor of psychiatry at the University of Leicester who led the study. He added that the findings were not conclusive and more research is needed.

None of the adults included in the study had an existing diagnosis of autism, though in a few instances relatives told researchers that they had suspected it.

In one case, a man said he had asked his doctor about the possibility but was told that a diagnosis in middle age would be useless.

After all, he had gotten this far without it.

Still, as more children are being diagnosed with autism, more adults are wondering if they have it too.

Karl Wittig, a retired engineer from New York, had always questioned why so few social skills came naturally to him.

A diary his mother kept in the 1950s suggests he was not an ordinary child.

"This last few weeks, he doesn't pile the blocks anymore," she wrote when he was 2. "He likes to put one next to the other, making a big row of 48."

Two years later, he talked nonstop about wires, switches, light bulbs and Thomas Edison.

Wittig went on to earn undergraduate and master's degrees from Cornell University and New York University in physics, electrical engineering and computer science. In the research laboratories where he worked, he felt he fit in.

"I went into a field full of eccentric people," Wittig recalled. "I was just another eccentric person."

Wittig said he eventually figured out how to behave in social situations - to refrain from correcting other people's mistakes, flaunting his math abilities or rambling on about his own interests. He married a former nun 18 years his senior. She died of cancer after two decades together. Wittig described the marriage as happy.

Still, he wanted to understand what made him different. So at age 44, he brought his mother's diary to a [psychiatrist](#), who evaluated him and concluded he had Asperger's disorder, a mild form of autism.

"I had been waiting for an explanation for these issues my entire life," recalled Wittig, now 55, who lives alone in the apartment he once shared with his wife. "Finally, here it was."

On the high-functioning end of the autism spectrum, it is possible to pass for "normal," or some semblance of it. Over time, experts say, many people with the disorder adapt to their surroundings. It helps to find a niche, a constructive interest or a job.

For some, the key is finding a guardian angel.

Mark Teufel said he could barely survive without Loraine Girard, a divorcee from Texas with whom he has lived for the last 17 years.

They met at the Magic Castle, a Hollywood club for magicians. Teufel, 57, who has a wispy beard and gray ponytail, makes contraptions used in tricks - polished works of art crafted from wood and metal.

He and Girard live in a rent-controlled apartment in Santa Monica. Tools, spare parts and papers are spread over every surface, with towers of boxes and plastic bins rising out of the rubble to create an indoor metropolis. It has reduced the hallway to a crawl space, cut off access to one bedroom and rendered the oven unusable.

"He needs everything out in the open to know where it is," Girard explained.

Teufel said he can't fill out a form, write a check or follow a news broadcast without Girard's help.

During a childhood that he described as "full of misery," he said he was

often picked on. At home, he would retreat to his room to build toothpick houses or perfect magic tricks.

When he graduated from Santa Monica High School in 1973, his father put him to work in the family business, a jewelry factory where he still works part-time, filing and polishing rings.

In 1999, his nephew was diagnosed with autism. Urged by his brother, Teufel went to a psychologist, who diagnosed Asperger's disorder and provided counseling for several years. He's adjusted to his condition, he says, even to other people's misconceptions about it.

"Most of the time I am treated like I am stupid," Teufel said, "but I am not."

Howard McBroom might never have been noticed but for a turn of bad luck.

His problems early in life - a speech impediment, chronic clumsiness - never raised great concerns, though they led to relentless bullying. He was a decent student and went on to earn a history degree at Indiana University, where he kept to his books and made few friends.

After graduation, he moved west and found work as a security guard. For the next 26 years, he worked the graveyard shift and lived in a Burbank apartment. He wasn't bothered by the hole in the floor or the festering mold.

He rarely traveled, except for a weekend bus trip once a year to watch an arm-wrestling competition in Petaluma, Calif.

As his sense of isolation and depression mounted, he became deeply involved in a neighborhood church.

He fantasized about finding a girlfriend or just going on a date, but had no idea how. "I was well aware that I was in a world full of people more capable than me," he said.

Then, in 2003, the security company went out of business, and he was unable to find a new job. He fell behind on his rent. He feared becoming homeless.

A church member introduced him to an advocate for the disabled, who suggested that he be evaluated to see if he qualified for social services.

Nearly half a century into his life, he was told he had autism. "I think I'm somewhere close to the outer range," said McBroom, now 56. "Not severely autistic but definitely not normal."

Graduation from school, the loss of a job, the loss of a parent or any sudden change can unhinge someone with autism.

"If there is a curveball thrown, they have trouble reacting to that," said John McGonigle, who heads an autism center at the University of Pittsburgh and who has diagnosed dozens of adults, including, recently, a 76-year-old.

"They don't make those adjustments easily," he said. "They don't problem-solve."

Had therapies been available when they were children, they might have had better lives, McGonigle said.

There has been little research into what kinds of treatment work best in

adulthood. McGonigle has been training therapists to recognize and treat the conditions that often accompany autism, such as depression, anxiety and attention disorders.

Some people with the disorder simply need a "life coach," he said.

In McBroom's case, once he had a diagnosis, the Lanterman Regional Center in Los Angeles found him federally subsidized housing and a social worker. He started reading books about autism. He reminded himself to make eye contact when he spoke to people.

In 2007, he joined the Lanterman board, representing clients of the center, which arranges state-funded services for the developmentally disabled.

One of his priorities is identifying more autistic people who have been missed.

Over the next decade, hundreds of thousands of children with autism will become adults. How they will fare - and how much it will cost to take care of them - is a matter of enormous concern for their families and for policymakers.

There is another group of people who are at least as needy: Undiagnosed baby boomers who soon will face life without the parents who have always supported them.

"Those are the people on the doorsteps of the service system," said Marsha Mailick Seltzer, an autism expert at the University of Wisconsin. "They may not have a diagnosis, but they are there."

An unknown number of families will face the predicament of Kay Duquette, 83, and her autistic daughter, Jeanne, 49.

"What will happen to her after I am gone?" said Kay, who is deaf and in failing health.

Jeanne's older brother, Doug, a tree care specialist who lives with them in Irvine, said he will eventually be responsible for her.

But Jeanne, who receives a monthly disability check, said she can imagine living by herself in an apartment with a few dogs.

"Somebody would have to help her with her checkbook," said her mother. "And I don't trust anybody. She doesn't know if a person has good intentions or bad intentions."

As a child, Jeanne was taken from specialist to specialist. She was tagged with a multitude of labels, none of them quite right. At first doctors ascribed her difficulties to "slow development" and "extreme shyness."

Teachers tried to help. "As you know, difficulty with language is central for Jeanne, and I have encouraged just as much verbalization as possible," one teacher wrote in 1969, when Jeanne was 6.

Later came diagnoses of depression, dyslexia and possible paranoia.

Doctors and teachers told her mother that Jeanne would eventually catch up.

In some ways, she did. At University High in Irvine, she routinely landed on the honor roll, despite her inability to do basic math. On one standardized test, she scored in the 93rd percentile in reading. She played viola in the orchestra and stacked books in the library.

She had only one friend - a boy who shared her interest in "Star Trek" - and he moved to Kansas.

Making matters worse, her parents were going through a divorce. At one point, she cracked, threatening her parents with a kitchen knife, which landed her in a mental ward for two weeks.

Later, she tried college, taking all the writing classes she could. But she dropped out after failing algebra and has lived at home ever since, without friends or a job.

Jeanne was 39 when her mother read a newspaper article about autism and took her to a specialist, who diagnosed it immediately.

Today she lives for her routines and obsessions: the civil war histories and fantasy novels neatly arranged on a shelf in her room; the massive jigsaw puzzles she works row by row; chores such as loading the dishwasher and cooking the side dishes for dinner; ESPN "Sports Center" and the sports section of the Los Angeles Times.

Her only regular contact with outsiders is when she walks Sakura, her Labradoodle, with neighbors each afternoon.

"I just listen to people talk about their lives," she said.

Looking back, Kay Duquette wonders how things would be different if her daughter had been diagnosed as a child.

What would her life have been like?

THE RISE OF A DISORDER

In the last 70 years, autism has gone from being an obscure condition to a familiar diagnosis.

1943

Dr. Leo Kanner publishes a paper about 11 children guided by a "powerful desire for aloneness and sameness." He later calls the condition "early infantile autism."

1966

A study in Middlesex County, England, estimates the rate of autism in children at 0.04 percent - the most commonly cited figure until the 1980s.

1967

Psychologist Bruno Bettelheim popularizes the theory that "refrigerator mothers" cause autism.

1977

The first of several studies of twins recasts autism as a largely genetic disorder.

1980

"Infantile autism" is listed in the Diagnostic and Statistical Manual of Mental Disorders - the first time autism appears as a distinct disorder.

1987

A more expansive diagnosis, "autistic disorder," replaces "infantile

autism" in the diagnostic manual.

1987

UCLA psychologist Ivar Lovaas gives parents hope with a study showing that intensive therapy can help autistic children.

1988

The movie "Rain Man," starring Dustin Hoffman as an autistic savant, raises public awareness of the disorder.

1991

The federal government makes autism a special education category, prompting schools to begin identifying and serving autistic students.

1994

A new edition of the diagnostic manual adds Asperger's disorder, expanding the autism spectrum to include many milder cases.

1998

A Lancet study suggests the measles-mumps-rubella vaccine causes autism. The finding was later debunked, though fear of a connection persists among many parents.

1999

California officials report 12,000 autism cases in the state developmental services system - a rise of more than 200 percent in a decade.

2005

Bob Wright, a top General Electric executive, and his wife, Suzanne, form Autism Speaks, now the world's largest autism advocacy group. It portrays autism as an epidemic.

2009

The CDC estimates that 1 in 110 children have autism spectrum disorders, up from 1 in 150 in 2007. Agency officials say the rise stems at least in part from greater efforts to identify the disorder.

2011

Researchers estimate that in a Seoul suburb, 2.64 percent of children have some form of autism, mostly undiagnosed, suggesting autism rates rise as people look for the disorder.

More information: *ABOUT THIS SERIES: Rates of autism have exploded over the last 20 years. In exploring the phenomenon and its repercussions, Los Angeles Times staff writer Alan Zarembo interviewed dozens of clinicians, researchers, parents and educators and reviewed scores of scientific studies. Zarembo, along with Doug Smith and Sandra Poindexter of the Times data team, also analyzed autism rates and public spending on autism in California.*

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