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What Happens When You Trust Too Much

By Tolly Moseley

"It would scare me to death to have him work there."

Terry Monkaba is talking about her son Ben, and the prospect of him finding a job at a Las Vegas casino. Many parents might feel that way, but Monkaba's anxiety goes deeper. That's because Ben, 28, has Williams Syndrome.

Once called "cocktail personality syndrome," Williams Syndrome—particularly as it affects children—has captivated science writers for the past decade. In 2008's *Musicophilia: Tales of Music and the Brain*, Oliver Sacks describes visiting Berkshire Hills Music Academy, where he was immediately received by unusually friendly children. "They all seemed extraordinarily sociable and inquisitive," he writes, "and though I had met none of these campers before, they instantly greeted me in the most friendly and familiar way—I could have been an old friend or an uncle, rather than a stranger."

Strangers were also the topic of Alix Spiegel's 2010 NPR series on Williams Syndrome, where she told the [story](#) of a nine year-old girl named Isabelle. In one segment, Isabelle, who has Williams Syndrome, practices role-playing exercises that teach her the concept of distrust.

"Hello little girl, do you want to see my puppy?" Isabelle's mom practices with her.

"No way," recites Isabelle obediently.

"But my puppy's so cute! Are you sure?" prods her mom, the "stranger."

"Yes," says Isabelle.

"Come over here, I've got some candy too!"

[*Sound of internal struggle from Isabelle*]

"C'mon, come into my car and I'll show you," her mom tempts.

And with that, after holding out against puppies and candy, it's the offer of companionship that finally breaks Isabelle down. "Ok," she relents, as though she can't help but accept.

But adults with Williams Syndrome have received less attention in the media, partially because their condition predisposes them to diseases that shorten their life span, like diabetes and congenital heart defects, and partially because, as a science writer, children who instantly tell you they love you make for adorable story subjects. Adults with Williams, however, have a vastly different set of challenges

than their younger counterparts. After a lifetime of parents and caretakers constantly watching out for their safety, can they learn how to protect themselves? Move independently in the world? And can they take on that hallowed marker of adulthood: a job?

To answer that last question, it's important to understand the scientific basis of Williams Syndrome, and what makes individuals with the condition pathologically vulnerable. Why does Monkaba, for example, fear her son Ben getting a job in Vegas? It has to do with the way his brain is structured, which diminishes his social wariness to an extreme degree—and for Ben, that could be dangerous.

The human body contains roughly 30,000 genes, but at conception, the deletion of just 26—a string comprising less than one percent of your genetic code—along chromosome seven results in Williams Syndrome. Their absence manifests in a variety of characteristics, and Dr. Colleen Morris, genetics section chief at the University of Nevada School of Medicine, is quick to point out that it's a "multisystem disorder"—meaning it affects lots of areas of the body besides the brain, and looks different on different people.

"That being said, there are some general commonalities," Morris says. "They get easily fatigued, and we're still trying to understand why. There's also a higher incidence of diabetes and hypothyroidism, as well as cardiovascular disease."

And behaviorally?

"Friendliness, oh my gosh. Lots, lots of social interest. High levels of empathy. Distractibility too, which makes it harder for them to focus and get work done."

Like Morris, Dr. Barbara Pober, a medical geneticist at Massachusetts General Hospital, was another one of the doctors turning her attention toward Williams Syndrome in the late '80s. In 1987, she began treating patients at Boston Children's Hospital, which opened one of the first Williams Syndrome clinics in the country. Today her patient base contains individuals of many ages with Williams Syndrome, including adults. Several don't have jobs.

"Sometimes that's due to external factors, like finding transportation, since most adults with Williams Syndrome don't live on their own and don't drive," Pober says.

The not-driving could be attributed to the fact that Williams Syndrome affects visuospatial construction, as evidenced by several studies, including [one published in *Brain* in 2009](#), of which Morris was a part. But there's something else going on here. On the job, just how easy is it to take advantage of an individual with Williams Syndrome?

Work is an arena where relationships are forged, and alliances are built. The modern office is a test lab for social discretion, where we quickly learn who we can trust, and who we should avoid. But for individuals with Williams Syndrome, who often trust indiscriminately, this can be a problem.

"I've had many hard experiences at my jobs," says Amy Koch, 48, a resident at Marbridge, a nonprofit residential community in Austin, Texas. "To tell you the truth, I was very hesitant about going for another."

Koch has Williams Syndrome, and has wanted a job for a long time. Six years ago, she found one at Seton Medical Center in Austin thanks to Marbridge, which adopted and funded a Project SEARCH

program: a Cincinnati-based internship training that helps adults with disabilities find work. But the opportunity arose only after Koch got a taste of workplace politics the hard way.

"I started working for my dad at his insurance agency, and the people there weren't used to working with someone with a handicap," says Koch. "They would treat me mean. They would say things that were so derogatory and hurtful, like I was retarded, that I couldn't make copies on the copier, couldn't do data entry. I started not wanting to get up in the morning, I was so hurt and angry."

So if logistics are tough and the social risks are many, how does this group of people find work?

It's important not to paint all individuals with Williams Syndrome with the same brush. Just like there are plenty of people without cognitive disabilities who couldn't care less about a job, the same holds true for this population. Nevertheless, job opportunities are there for individuals with Williams Syndrome, and job coaches are starting to work with more employers—not just employee hopefuls—to prep them for a harmonious relationship.

The medical profile of Williams Syndrome reveals two tendencies: high sociability, and—relative to IQ score—strong language and verbal skills. Often, there's also a decreased sense of social threat. That's been confirmed by many researchers, but includes a 2010 [study](#) that looked at Williams Syndrome children and their ability to detect angry faces (low). All of which add up to a potentially delightful employee, but one who may easily be taken advantage of.

"They'll often overdraft their bank accounts buying lunch for coworkers," says Monkaba, Ben's mom, who is the executive director of the Williams Syndrome Association.

"We see it happen a lot, unfortunately. People will ask them to buy them something, and they just won't think twice about it."

This is where a job coach comes in. Wariness might be something most of us take for granted at work, even if we love our job and trust our coworkers. But lunch is lunch, and we're not shelling out for work buddies every day. But speaking of relationships, another lesson for this often highly social group is...

"Focus!" cries Robert Ackerman, 46, another Marbridge resident with Williams Syndrome. He's been a dishwasher at the Barton Creek Resort and Spa in Austin for eight years, but admits it took him a while to not get distracted by his coworkers.

"I go in, I put on my uniform, I swipe my card, I clean plates from the night before"—here he pauses to demonstrate the machinations of the task—"I put them up to dry, and wait for the next dishes. And I stay there. And I do it over and over again!"

Which might sound, well, boring. But Ackerman loves the ritual. He also loves chatting with his coworkers, which is why focus was the main thing he and his job coach worked on. Koch also enjoys the ritual of her job—delivering equipment and linens to doctors and patients—but more so, she likes feeling accomplished.

"I want my parents to say, 'Hey, look at Amy! She's really getting somewhere,'" she says. "I'm tired of people thinking that none of us can do anything. Excuse us, yes we can."

That's why 2013 was a big year for Koch. She won an award from Women and Girls Lead, a national female leadership campaign that partnered with a local public television station. That year, they

received 70 nominations, and Koch was one of eight recognized. She was even invited for a TV interview.

"I was in tears when I found out," Koch says. "I was like, wow. They think of me like that?"

The thing about having a highly social mind is that anxiety lurks just around the corner. High levels of anxiety are also reported with Williams Syndrome, whether it's the eagerness to please you, or simply to know when Christmas is coming. But now that employers and job programs are starting to better understand the needs of people with Williams Syndrome, the workplace might be getting more amenable for them. Still, for these individuals, does going to work mean learning to temper their trust?

"I'm very wary now of trusting anyone," Koch says. "I don't want to go through what I went through at my past jobs. I guard things. I'm quiet. I'm cautious, period."

Is she happy being less social?

"When I come home, I'm on top of the world," she says. "I have done all the things I was hired to do. I did it. And that's enough."

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