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MAGAZINE

For autistic youths entering adulthood, a new world of challenges awaits

Finding work, love, and independence can be especially difficult for those on the spectrum. BY JUDITH NEWMAN PHOTOGRAPHS BY LYNN JOHNSON

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'Guys! Remember: Above the neck! OK, go.'

We are practicing giving compliments at the <u>PEERS Dating Boot Camp</u>, a program for teens and adults with special needs who hope to find love. The participants, many with autism, are mostly in their mid to late 20s, but seem years younger. They come alone or with parents, caretakers, sometimes a sibling. Almost all live with their families. There's lots of unfortunate facial hair, T-shirts from obscure bands (Radioactive Chicken Heads), noise-canceling headphones for the hearing-sensitive, plushy key rings hanging off backpacks.

Reading social cues is difficult for those on the spectrum, so everyone here wants to know the rules. And when it comes to dating, there are a lot of rules. Dating coaches, either doctoral students or administrators in the neuroscience program at the University of California, Los Angeles are trying to explain them.

A slight man in plaid flannel and khakis that seemed to be ironed on, frowns as he scans a female dating coach, looking for an in. His face brightens when he notices a tattoo on her ankle.

"Hey! I see you have a lambda. You like biophysics? Me too!"

"Neck up, I said. But OK, great!" the male coach leading the exercise says. "That was very nice; you established common interest."

The young man beams.

The male coach turns to a baby-faced man in a neat button-down shirt and asks him to try complimenting the female coach. She smiles encouragingly; he breaks into a flop sweat. Finally, words spill out: "I. Um. I ... like the way your earrings sparkle against your pale white skin."

"Poetic!" the male coach says. "But we want to stay away from skin color, race, religion, and ethnicity at first, you know." The man, who is brown-skinned, nods and take notes. He was eager to explain himself, though. "If she is very pale, that means she's not out in the sun all day, working in the fields, like she's royalty."

Not helping, dude. Still, that would win my heart.

Adulting is hard. Adulting as a person with autism spectrum disorder is harder.

Autism is a complex neurological condition that includes impairments in social interaction, language, and communication skills, combined with rigid, repetitive behaviors. The range of disability (and ability) is huge, which is why it's called a "spectrum" disorder, and the number of those affected is growing. In 2018 the U.S. Centers for Disease Control and Prevention <u>published a study</u> that found the prevalence was one in 59 eight-year-olds, a 15 percent increase over two years. Why? That's a subject of heated debate. But one thing is certain: There's a rapidly growing population of adults with autism. In the United States, more than 700,000 will reach adulthood by 2030, according to <u>Paul Shattuck</u>, an associate professor of public health at Drexel University. Services for autistic adults fall off the cliff after they reach age 21. What will all these people do in their daily lives?

(Read about a discovery that could help doctors detect autism earlier.)

Data about employment vary significantly, but more than eight out of 10 autistic adults are thought to be unemployed or underemployed. Studies also show that the same number desire a romantic partner, but only a third to a half have one and fewer ever marry. If Freud was right—that love and work are the foundation of our humanity—we need to do better.

These issues are very personal to me. My autistic son, Gus, just turned 18. He's the kindest person you'll ever meet, with a confounding combination of strengths and weaknesses that makes me unable to guess if he'll ever live on his own. Why can he play the piano beautifully but can't cut his own food? Why does he love social media but can't help friending absolutely everyone, so his circle includes "Sex Worker Aboud" and enough sketchy "friends" to qualify for the FBI's watchlist? For that matter, why can he navigate New York City so easily but can't be trusted with money because he gives it away to anyone who asks? Recently I received a fraud notice on my credit card. It appeared the thief's purchases consisted of thousands of dollars of donations to Democratic causes. Yes, it was an inside job. When Gus was busted, he just said sadly, "But ... I thought you wanted to ditch Mitch."

I think a great deal about what it will take to make my son independent. Some days, it's all I think about. I'm not alone. If there are more than an estimated four million autistic people in the U.S., there are surely a great deal more than four million neurotypical people who love them.

As Gus ages into adulthood, the list of his challenges that worry me grows longer. But the two questions that keep me up at night are: Will he find love, and will he find work that means something to him and allows him to at least partially support himself? I set out to see what I could learn.

About a year ago a note was passed on to me. It was from a teacher at Gus's school. I had just published <u>To Siri With Love</u>, a book about raising an "average" kid on the spectrum, and I guess I did a lot of fretting. "I don't know wtf Judith Newman is talking about," the teacher wrote. "Gus will get a real job! He isn't going to need anyone's charity."

That's the best note I've gotten, ever.

It's true that more and more companies are recognizing the unique, and sometimes extraordinary, talents of autistic people. Some have set up special recruiting divisions. Microsoft and HP hold multiday hiring events to recruit autistic engineers and data scientists; JPMorgan Chase and Deutsche Bank also have seen the tremendous advantages of hiring those whose social skills may be iffy, or even nonexistent, but who have technical gifts. This is wonderful, but such whizzes represent only a small subset.

What about the regular (autistic) Joe, or Gus?

A lot of mom-and-pop concerns are filling this niche, generally started by a business-minded parent with an autistic child. On any given day I hear about new ones. Good Reasons in North Salem, New York, is a dog treat company that helps autistic people realize their "pawtential." (Note to owners: Just because you're helping people like my kid doesn't excuse this pun.) Coletta Collections in Washington, D.C., sells costume jewelry and hand-dyed scarves, featuring its artisans in profiles on its website. Two bookstores in New Jersey called Words, owned by a couple whose son is on the spectrum, employ mostly autistic help. Gus has interned at Luv Michael, which makes an organic, gluten-free, nut-free granola named after the autistic son of the founders, Lisa Liberatore and Dimitri Kessaris. Gus, who has the autistic person's very limited palate, doesn't eat granola. But his paycheck? He ate it up.

Luv Michael and many similar businesses are nonprofits. I wondered whether there were businesses that predominantly hired people on the spectrum and yet were still trying to make a buck.

I heard about Rising Tide Car Wash in two ways. First, from its viral video. In it, young adults washing cars combine insane car-cleaning attention to detail with, well, dancing. And then, from a friend in Parkland, Florida, who is a regular customer. "People don't go there to help autistic kids," she said. "People go because your car comes out spotless."

Tom D'Eri is the co-owner; his autistic brother, Andrew, works there and was the inspiration. In 2011 D'Eri and his father, John, started researching a business that could be profitable and hire young adults like Andrew, who's 27. Rising Tide opened in 2013. A second opened four years later.

When I visit, D'Eri asks a few workers to gather in the break room.

Luke Zenda, 19, is a great worker, with no filter. This is not just an educated guess. "I'm really good at this, and I have no filter," he says cheerfully, by way of greeting. His favorite part of the job? "Sometimes the breaks and sometimes the rain and sometimes the people. You have some things happen that make you question life."

I was a little afraid to ask what he meant, but I didn't need to ask. You've got the odd customer: "I once saw one just wearing a bra and just pants." And special items customers leave behind: "I found a condom in there, already used."

"What do you do in your spare time?" I interject quickly.

"After working here, it's like I want to go to sleep, and don't have to do cars," he replies, though he uses an epithet to describe the cars that captures both the exasperation and pride of the workingman.

Initially, D'Eri wasn't sold on the idea. "I was not comfortable with the idea of employing people with autism," he tells me. "It was something that scared me for sure." The self-described myway-or-the-highway manager had to learn to really listen so he could understand his employees. "You see, oh, oh my God, Melvin went from I think I was gonna have to fire him and I couldn't imagine a world where he was gonna be a good employee—this kid is now a rock star. He's like—I wish I had a hundred of him."

Jeff and Anthony shamble in. Both men are 32. When he's not cleaning cars, Jeff says he's a voice-over artist in training; he's also into puppetry. Anthony does a podcast called "A-Log on the Airwaves," playing comedy songs on *madmusic.com*; he also does voices and gives me his Bernie Sanders. Anthony goes for some unprintable Bill Clinton banter, and then they both try out their Mr. T impressions. D'Eri gently steps in: "This isn't a competition, gentlemen."

Asked what they like best about working at the car wash, Anthony answers unhesitatingly: "The camaraderie. So, like seeing the same faces," he says, "and also having someone to talk to while you're working. So, days when it gets boring. Right, Jeff?"

"Yeah," Jeff says. "We talk about what comes to our minds. And we speak from the heart."

That lack of inhibition had worried D'Eri. But, he says, "we have way more behavioral issues with our typical employees."

It's just a matter of knowing the people who work for you, the quirks that might become a thing. "When we talk to other businesspeople about this, it's, 'You can really look at your employees with autism as extreme users of management and leadership,'" D'Eri explains. "What they need is more observable than a regular employee. But what they need is no different than what anybody else needs. You can just see it a lot easier."

"They're friends," Steven Nesenman says emphatically.

We're trying to look like we're just strolling casually through this street fair in Lake Worth, Florida, even though what we're doing is closer to trotting. Nesenman is grim and determined; he doesn't want to lose sight of his daughter, Leah, for a second. Not because she would get lost, but because she is with her "friend," Brandon, and anything could happen. Maybe once or twice things did happen. But not on Dad's watch.

Leah is a gentle, shapely girl with piercing green eyes; she paints peace signs obsessively, collects lizard and frog figurines, and makes jewelry out of glass. She works at the Chocolate Spectrum, a candy shop—another business begun by a parent of an autistic child. Brandon too is an artist; he paints tiny, brilliantly colorful cartoon animals, flowers, and word diagrams. He sells his work online and in the Artists With Autism gallery in Pompano Beach, which was started by his mother and which he sometimes runs on his own. The two met seven years ago in an art class. They are in their mid-20s.

"I was born with a talent," Leah says, when we catch up. She can't exactly explain how she selects her glass, but clutches her necklace and says, "I like the colors. It makes you feel good. It's pretty. I like the greenness." They admire each other's work a great deal.

Earlier that day I'd visited Brandon in the small, airy apartment he shares with his mother, Cynthia Drucker. Brandon is a burly, handsome boy with a cowlick and a broad smile. When he was younger, he was impulsive, and while he never hurt anyone, he would slam things when he was angry. Drucker keeps a bound copy of Brandon's school reports from kindergarten on; sometimes she'll flip through them, to remember how far he's come.

Being unable to discern people's intentions combined with being a typical, amorous young man has gotten Brandon into more than a little trouble. A couple of years ago, Drucker felt Brandon was ready for a debit card. She learned she may have been a little hasty after he ran up \$1,000 plus overdraft charges at a strip club.

Soon after, he brought home a prostitute who was looking for a place to hang out for a while, and his mother actually agreed. ("I thought I was gonna save another soul. What can I say?") When his money ran out and the woman wanted nothing more to do with him, Brandon was traumatized. But Drucker saw an upside. "Because he's had the experience, he knows what to do. He knows what the condom is only because of the experience with the prostitute," she says. "Something good came out of that. But for him to tell about the experience on the phone to his buddies, it's like, oh, my God." Drucker is, to put it mildly, a glass-half-full mom.

Brandon is eager to talk about Leah and the life he hopes they might someday share.

"I guess we would just take care of ourselves, and then, like, if she's ever sick, then I would just be giving her medicine," he says. He also promises to cook and do the laundry. Does this cover everything? Maybe not, but it's a good start. Brandon also says he wants to live with Leah and with Maria, another girlfriend. Uh ... well ... autism or not, Brandon isn't the first man to entertain such fantasies.

When I talk with Leah about her dreams for a loving relationship, she expresses the hope that it would be a step toward independence.

This talk makes her father deeply uncomfortable. What a struggle it is to raise an autistic child, he says, and what a toll it takes on a marriage. (He and Leah's mother are divorced.) I'm hardly a Pollyanna, but I see in Leah and Brandon what I desperately want for my own son. I try to get Nesenman to focus on what he has: A daughter who loves to create, holds a job, may need supervision, and maybe isn't up to caring for children, but seems to have a pretty good shot at having a relationship and living independently.

Nesenman doesn't see it that way. Well, yes, she has a job, but it doesn't pay, and anyway, she doesn't really understand the value of money.

Isn't he happy, though, that his daughter's found romance?

"You can't call it romance," he says firmly, "but it could be support, feeling secure, knowing what tomorrow's going to be like. You know, but that's the hard thing with autistic people. They want regularity."

I can't pretend to be objective; while understanding every worry he has, his attitude made me want to cry. Yes, autistic people want and need regularity. But is there anything wrong with wanting love too?

Frank is kneading dough at a pizza joint at Rutgers University in New Brunswick, New Jersey. He is mostly nonverbal and severely autistic. What I am watching is a little bit boring and a little bit miraculous.

When Frank became one of the first participants in the <u>Rutgers Center for Adult Autism Services</u>, he exhibited two behaviors pretty much nonstop: clutching his hands and screaming at the top of his lungs. These would not seem to bode well for gainful employment. But the Rutgers team discovered something else: Frank loved books, and he loved order. The program staff thought he'd love the library—but then, there was the screaming issue. Remarkably, saying the call numbers to himself while shelving the books competed with—and eventually squelched—the motivation to yell. But what about that clutching?

That's why Frank is spending his afternoons at the pizzeria. With a bit of finessing, Frank has been taught to make dough and form it into small rounds, which are then frozen. If you are forming pizzas, repetitive clutching is a feature, not a bug.

Eyes narrowed, Christopher Manente, executive director of the center, which is part of the Graduate School of Applied and Professional Psychology, watches Frank and his coach intently. "You know, people have this preconceived notion about autistic people, they're <u>Temple Grandin</u> or *The Good Doctor*—or they're completely debilitated. The extremes. So sometimes when I approach a company and ask them to take on one of our people, they think of it as just extra work. But it's really interesting, what can be worked out."

The Rutgers program conducts research and training for autistic adults across the spectrum—not just for specific pockets. It's the first program of its kind at a U.S. college. Twelve students are enrolled, but the program hopes to take up to 60. For now, they are commuters, but the idea is to create a live-work community where graduate students being trained to work with autistic adults live side by side with them.

Manente and I run around the campus, meeting trainees. Scott's favorite part of his waitering job at the diner is rolling napkins around silverware. Michael is in the fine-dining Rutgers Club, where he complains loudly that the job he wants is to be a greeter, but at the moment is utilizing his meticulous attention to detail to vacuum like a dervish. Stan, who is into aquariums and wizardry, works in the campus computer store; he struggles a little with the service aspect of the job because he is given to issuing very opinionated reports on the news of the day. They all have their eccentricities.

Surely they're more trouble than they're worth, right?

Manente introduces me to Sebastian Nieto, the manager of the Rutgers Club. We cram into his tiny photo-cluttered office. "Look, we're a college, a lot of times we're giving 'regular' students their first work experience," he says. "We put all this time and energy into training them. So why is this so different?" Nieto, who is from Argentina, looks at this from the perspective of an immigrant. "You come from another country, you don't know the language, you don't know the ways," he says. "You may be good, and you may be awful. But someone's got to put a little bet on you, even if it takes more work to get you where you need to be."

Nieto, who's familiar with Scott's work at the diner, notes that he wraps napkins around silverware better and faster than anyone he's ever seen—and furthermore, he really, really likes doing it. "C'mon, hiring autistic people?" he says. "This is a no-brainer."

The dating camp is the brainchild of Elizabeth Laugeson, an associate clinical professor at the UCLA Semel Institute for Neuroscience and Human Behavior. A lot of social skills programs, a common treatment for people on the spectrum, are not that effective past a certain age.

"Most of the programs are focused on younger kids," she says. "Do you think that the social skills that you need when you were in grade school were different than the social skills you needed in middle school, in high school, and adulthood? Completely different."

Laugeson leads the boot camp all weekend, and she is kind, direct, and unflappable. Her mission: To decode the social-romantic-sexual world. "You don't get to date everybody, and not everybody gets to date you," she says, repeating it like a mantra.

Every possible facet of approaching another person is broken down and role-played: Flirting with your eyes (how to glance and look away—as compared to never looking in someone's eyes or staring like a zombie); getting into and out of conversations smoothly ("I gotta go to the bathroom" was revealed as a less-than-ideal exit strategy); the proper distance to stand during conversation (one woman was told she was too far away, then crept within six inches of the coach's face).

Slovenliness was emphatically discouraged. "It's disrespectful to your date," says Laugeson. In what I consider comical understatement, she says of people without good hygiene: "They rarely get a date."

The questions flew fast and furious. The participants want concrete answers in this, the most fluid of arenas. Laugeson tries to supply them. One important rule: If you ask someone out and they don't respond, you can ask once more and that's it. A petite woman in a 1950s-style plaid skirt raises her hand. "So ... two messages a day?" "No. Two messages," Laugeson says. "Or a week?" "No." Trying again, the woman asks plaintively, "Just two messages an hour?" "Sorry," Laugeson replies.

There are rules even this psychologist can't supply, like the odds of getting a goodnight kiss on a first date. "What's the percentage of times you get the kiss?" asks a math-loving guy.

Several people want to know whether they should disclose their autism diagnosis. For this, Laugeson says, there is no rule. For some it's a yes. They are out and proud. For some it's a no. But if you do tell, she says, "don't make it a negative. Say what it means to you." She tells them to say all the good things, like, people with autism tend to follow rules, they tend to be loyal, they will tell you what they're thinking.

It's a lot for these daters-in-training to take in, but they're hopeful. Me too. For all of them, for our society, for my son—and especially for the bespectacled young man sitting next to me, who nods and mutters happily under his breath: "I can do this. I am boyfriend material."

Judith Newman wrote To Siri With Love, a best-selling memoir about her autistic son, Gus. Lynn Johnson, a frequent contributor, last photographed influential women around the world.

Correction: The correct name of Rising Tide Car Wash co-owner is Tom D'Eri.

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