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# How to navigate adulthood on the autism spectrum

A dearth of research on, and services for, autistic adults compounds social and emotional challenges

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When it comes to what we know about the adult years for autistic people, the research is either minimal or nonexistent. “We know the most about the transition period into young adulthood,” said Gregory Wallace, PhD, an associate professor at The George Washington University, who studies life

outcomes of autistic adults. "As you go into middle and older adulthood, we know almost nothing."

Research has largely focused on understanding and diagnosing autism in children and teenagers, which has led to increased awareness, earlier diagnosis, and better treatment for children and teenagers. In a pair of new reports from the Centers for Disease Control and Prevention, the prevalence of autism diagnoses among children has been estimated to be 1 in 36, a significant increase from previous years (Maenner, M. J., et al., *MMWR Surveillance Summary*, Vol. 72, No. 2, 2023 (<http://dx.doi.org/10.15585/mmwr.ss7202a1>)). These new diagnoses reflect a more diverse group of children, including a larger proportion of autistic children without intellectual disabilities. As these children grow up, they will continue to need various forms of support throughout adulthood.

Although there has been a shortage of formal research on autism in adults, there are some general themes that are starting to emerge, both from reports by the autistic community and from the limited studies that are available. Although autistic adults face a number of significant challenges when it comes to navigating adult life, "What I've noticed, through the years I've been working with people with autism, is that they struggle at the same transition points that everyone else does," said Valerie Gaus, PhD, a psychologist who specializes in working with autistic adults. "They just might have different specific issues."

Some of these challenging transitions include entering college (managing a higher level of independent work than high school), entering the workforce (learning a brand new set of workplace skills), learning to live independently, finding and maintaining friendships and romantic relationships, starting and raising a family, and caring for elderly parents. Although these struggles tend to mirror those of neurotypical adults, some of the features of autism, such as sensory issues, difficulties navigating neurotypical social norms, and challenges with executive functioning, can add extra difficulties to an already challenging situation.

# The service cliff

When Sam Wolfe, an autistic adult based in Texas, graduated from high school, he struggled with the transition. Wolfe, who was diagnosed in 1992 at the age of 4, was able to receive intervention services and accommodations throughout his school years. However, once he graduated from high school, the available services became minimal, an effect called the “service cliff.” The only support available to him was a state-run program that helped him find his first job at a local grocery store. But that was where the help ended.

After 10 years of working at his first job, which paid just a little bit above minimum wage, Wolfe qualified for a job program offered by another grocery store that offered additional training and paid a living wage. He’s been working there ever since, in a job that is a better fit for his particular needs, with a boss he describes as supportive. For the additional help that he needs, his family fills in the gaps, which includes living in a separate apartment attached to his mother’s house.

Wolfe’s story, where the bulk of his support needs are met by family and friends, rather than by a formal government or community service program, is very common. He’s also very lucky, as he’s been able to find a good balance, which includes full-time employment and a safe home environment. “A lot of people are relying on unpaid help from family or friends,” said Zoe Gross, the director of advocacy at the Autistic Self Advocacy Network. “There’s a lack of services available to adults.” This drop-off in services after graduating from school is one that, for many autistic adults, has a major impact on where they can live and what jobs they can do.

# Compensatory strategies

In a recent study, researchers looked at social competence measures in a longitudinal cohort of 253 autistic individuals, following them from age 2 to 26. What the researchers found was that social competence measures increased with age, and higher levels of social competence were directly correlated with

adult outcomes such as having a job, living independently, and maintaining relationships (Clarke, E., & Lord, C., *Development and Psychopathology*, 2023 (<https://doi.org/10.1017/S0954579423000664>)).

“As individuals continue to grow and develop, how autism presents, or what autism looks like in a person, really changes,” said Vanessa Bal, PhD, an associate professor of psychology at Rutgers University, whose research focuses on life outcomes in autistic adults. For many autistic adults, they will continue to learn and come up with various strategies for navigating major challenges in life. Even without formal support or training, their competence at, say, age 60, will outpace where they were at age 30, but many psychologists believe this growth could be greatly enhanced by additional research on these years. “What we really need to do is study adult life as a developmental period,” Bal said.

In Gaus’s experience, many of her older patients, a number of whom grew up without a diagnosis, have often come up with some very creative solutions for navigating the major challenges in their lives. Examples of this creativity include leveraging special interests to cultivate a career, adjusting their schedule to fit their needs, or modifying their wardrobe to account for tactile sensitivities. This creativity is often borne out of desperation, something that can exact a very high toll on the individual. But these challenges are also learning opportunities that can help pave the way for other autistic individuals. “I’m always struck by how much [a patient] has taught themselves,” Gaus said. “The first thing I do is learn about all of the tricks they have already taught themselves, and then we just build on that.”

## Stress and masking

Autistic adults report a higher level of perceived stress compared with the general population, according to a study conducted by George Mason University research assistant professor Goldie McQuaid, PhD, and colleagues. The researchers surveyed 713 autistic adults whose higher levels of perceived stress compared with non-autistic adults were significantly associated with

decreased independence and quality of life, such as struggling to maintain full-time employment, being unable to live independently, and suffering from issues such as anxiety and depression. Compared with autistic men, autistic women report even higher levels of stress (*Autism Research*, Vol, 15, No. 8, 2022 (<https://doi.org/10.1002/aur.2779>)).

One major stressor is handling social situations, during which many autistic adults feel pressured to participate in masking, or social camouflaging, in order to fit in. “You’re ‘passing’ in certain settings, but that can be a big psychological burden,” said Wallace, one of the authors of the paper. “The correlational evidence is very consistent, showing that masking and camouflaging are linked with poorer mental health.”

Although masking is correlated with poorer mental health, it can also be a survival mechanism, one that is very hard to stop. “Unmasking is one of the hardest things to do as an autistic person,” said Rebecca Faith Quinn, an autistic actress based in Los Angeles. “I have been trained to put on this persona of who I am for my whole life, because if I don’t, it means danger for me.”

Autistic practitioner Karissa Burnett, PhD, who specializes in therapy and assessment for neurodivergent patients, notes that for many autistic people, masking can start so early in childhood and become so ingrained, that they often reach a point where they don’t know where the masking ends and their authentic selves begin. For example, a small child might start suppressing their movements due to fears of being punished, or they might force themselves to stay quiet rather than share their unique ideas to avoid harsh reactions from their classmates or teachers, without ever consciously making the effort to do so. “A lot of it tends to be unconscious,” Burnett said.

Masking is inherently stressful for neuroatypical adults, since on some level most social interactions feel like performances where any misstep could mean ridicule or rejection. According to Burnett, “Autistic people often internalize that their natural ways of thinking and behaving are unacceptable, so they become externally focused, constantly monitoring themselves and their

environment in hopes of seeming ‘normal.’” In addition to the inordinate amount of energy this process takes, masking also means there is “implicit shame about the autistic true self underneath, which is also stressful,” she emphasized.

[**Related:** [An ADHD diagnosis in adulthood comes with challenges and benefits \(/monitor/2023/03/adult-adhd-diagnosis\)](#) ]

Besides masking, other types of stress involve dealing with the stigmas associated with being “different” and navigating employment and personal finances in a society with limited services, Gross said. “Just living in the world is more stressful for autistic adults,” she explained.

## Psychiatric comorbidities

Autistic individuals are also at risk for psychiatric comorbidities including attention-deficit/hyperactivity disorder (ADHD), depression, and anxiety. “Co-occurring conditions can have such a huge impact for people with autism as they transition to adulthood,” Wallace said. “Certain co-occurring conditions end up really presenting barriers and challenges to acquiring and keeping jobs.”

For autistic adults, the current and lifetime prevalence of anxiety are estimated to be 27% and 42%, respectively, while the current and lifetime prevalence rates for depression are estimated to be 23% and 37% ([Hollocks, M., et al., \*Psychological Medicine\*, Vol. 49, No. 4, 2019](#)

<https://doi.org/10.1017/S0033291718002283>). Autism is also highly comorbid with ADHD, with an estimated comorbidity rate of up to 70% ([Federico, A., et al., \*Disability and Health Journal\*, 2023](#) <https://doi.org/10.1016/j.dhjo.2023.101512>).

For adults who were diagnosed as children, although they may have both disorders, they may have only one formal diagnosis because a dual diagnosis was not allowed before the publication of the [Diagnostic and Statistical Manual of Mental Disorders \(Fifth Edition\)](#)

<https://www.psychiatry.org/psychiatrists/practice/dsm> in 2013.

As Wallace notes, the old school notion of ADHD was that it was a disorder that made people unable to focus, while autism was a disorder that made them unable to stop focusing. “That was simplistic,” Wallace said. Instead, both autism and ADHD affect a person’s ability to control their focus, with the two conditions sharing a number of overlapping features. For autistic adults who also have ADHD, this presents its own challenges, which includes issues with time management, organization, and task-switching.

In terms of psychiatric comorbidities, the age of diagnosis may make a difference. Researchers found that adult-diagnosed autistic individuals reported a higher number of psychiatric diagnoses than their childhood-diagnosed counterparts (Jadav, N., & Bal, V. H., *Autism Research*, Vol. 15, No. 11, 2022 (<https://doi.org/10.1002/aur.2808>)). “Adults who were diagnosed as adults have much higher rates of co-occurring depression and anxiety,” said Bal.

Four years ago, when Burnett was finishing her PhD in clinical psychology, she was diagnosed with autism. Having been twice misdiagnosed previously, she had first-hand experience with the misconceptions surrounding what autism can look like in adults. Eventually, once Burnett found an expert who was more familiar with autism in women, she finally received a formal diagnosis, one that helped give her context for some of her major life struggles. “It was an extremely formative and powerful experience,” said Burnett, who is currently a practicing psychologist in Boston.

Although the reasons that there are more psychiatric diagnoses in autistic adults are still unclear, it is likely to be the result of multiple factors. Autistic symptoms are often misdiagnosed as other conditions or comorbid conditions develop, such as anxiety and depression, due to masking and a lack of diagnosis and treatment. “For some people, not having an explanation of how to understand themselves is really difficult,” Bal said.

## Autistic burnout

In addition to these comorbidities, the stressors of navigating a world that isn’t designed for autistic individuals can have a cumulative burden. This includes an

emerging concept in the research field of what is called autistic burnout, which is a combination of fatigue, exhaustion, and limited functionality. “For many of us, it is inevitable,” said Lydia Brown, a disability rights attorney and senior advisor for the Autistic Women and Nonbinary Network. “It’s very common during transitions and major life changes.”

Autistic burnout can happen for a number of reasons, including being overwhelmed at work; having difficulties with personal relationships, friendships, or romantic partnerships; or juggling the demands of raising a family. Although these transitions are tough for everyone, autism adds some extra challenges, such as heightened sensitivity to stimuli; the energy-intensive nature of social interactions; and difficulties with executive functioning, including organization, time management, and adjusting to changes in routine. “It all really takes a toll,” Burnett said.

Some of the workplace challenges can include having to deal with uncomfortable sensory stimuli, such as flickering lights or the humming of air conditioner units, the unpredictability of interacting with strangers, the unspoken rules of the workplace, or a changing schedule. “All of this is much more effortful than it would be for another employee in the situation,” said Katherine Loveland, PhD, a professor of autism research and treatment at UTHealth Houston and the founder of the C.L.A.S.S. Clinic (Changing Lives through Autism Spectrum Services), which offers diagnostic and treatment services for autistic teenagers and adults.

In a recent survey of 141 autistic adults, researchers found that autistic burnout is linked to masking and depression. Whether the burnout is caused by the masking or depression or the masking and depression are symptoms of other underlying causes is still an unanswered question (Arnold, S. R. C., et al., *Autism*, 2023 (<https://doi.org/10.1177/13623613221147401>)).

[***Related:*** [Helping people with autism reach their full potential](/monitor/2020/07/autism-potential) (</monitor/2020/07/autism-potential>)]



# Unemployment and underemployment

For many autistic adults, finding and maintaining employment can be a major issue. Compared with their non-autistic peers, autistic adults face a higher rate of unemployment, even after controlling for factors such as age, gender, health, and intellectual disability (Nord, D. K., et al., *Research in Autism Spectrum Disorders*, Vol. 24, 2016 (<https://doi.org/10.1016/j.rasd.2015.12.013>)). For those who are employed, they are often underemployed, working fewer hours and at a lower pay than their non-autistic peers. The reasons for this can be complex and multifactorial, starting with the interviewing process, which often prioritizes an unspoken set of social expectations that autistic candidates may fail to grasp. This can lead hiring managers to unknowingly discriminate against autistic candidates who otherwise have adequate qualifications or experience.

“It can be very difficult to prove discrimination, especially in hiring,” Gross said. “It’s all about how you click socially with your interviewer,” which can lead to an autistic individual getting rejected for claims that the candidate would be a bad cultural fit or that their vibe was off. “That’s unfortunate because there are a lot of autistic people who can do the job they are interviewing for,” Gross said.

Once an autistic individual is in a job, there are additional hurdles, including asking for, and receiving, accommodations or navigating unspoken social norms of the workplace.

## Barriers to mental health care

For autistic adults, accessing health care, including mental health services, can be complicated by a scarcity of practitioners familiar with autism. “There are not enough psychologists trained to adequately support autistic people, particularly adults,” Bal said. Instead, many psychologists will often refer autistic adults to practitioners with expertise in autism who usually have exceptionally long waitlists.

Quinn encountered this issue when she first sought therapy. “People hear ‘autism,’ and they assume there’s no way they can understand and help me unless they’re an expert on autism,” she said. “Expecting experts to be the only people to help autistic people does a great disservice to autistic people because it means we have far fewer options than everyone else.”

Eventually, Quinn found a therapist who didn’t have experience working with autistic adults but was willing to learn. With Quinn’s permission, they have tried both dialectical behavior therapy and eye movement desensitization and reprocessing therapy, both of which Quinn has found helpful. As Quinn has also discovered, her therapist’s lack of autism expertise meant she was treated as a person rather than a stereotype. “A lot of autism experts get so focused on the autism that they forget they are looking at an autistic person,” Quinn said. “That is a very dehumanizing experience.”

For Burnett, the misconceptions she encountered during her diagnostic journey ultimately served as motivation for her as she finished up her internship and post-doctoral training. Prompted by the profound impact that an accurate diagnosis had on her own life, she opened her own neurodiversity-affirming practice called Divergent Pathways, where her goal is to offer the same care and attention she finally received. “I very much strive to validate and empower autistic adults who have been long missed,” Burnett said.

## Further reading

[What I mean when I say I’m autistic: Unpuzzling a life on the autism spectrum](https://www.amazon.com/What-Mean-When-Say-Autistic/dp/BOBJYSTPW2)

<https://www.amazon.com/What-Mean-When-Say-Autistic/dp/BOBJYSTPW2>

Kotowicz, A., Neurobeautiful, 2022

[Unmasking autism: Discovering the new faces of neurodiversity](https://www.amazon.com/Unmasking-Autism-Discovering-Faces-Neurodiversity/dp/0593235231)

[https://www.amazon.com/Unmasking-Autism-Discovering-Faces-](https://www.amazon.com/Unmasking-Autism-Discovering-Faces-Neurodiversity/dp/0593235231)

[Neurodiversity/dp/0593235231](https://www.amazon.com/Unmasking-Autism-Discovering-Faces-Neurodiversity/dp/0593235231)

Price, D., Harmony, 2022

## Neurotribes: The legacy of autism and the future of neurodiversity

(<https://www.amazon.com/Neurotribes-Legacy-Autism-Future-Neurodiversity/dp/0399185615>)

Silberman, S., Avery, 2016

## Is this autism? A guide for clinicians and everyone else

(<https://www.barnesandnoble.com/w/is-this-autism-donna-henderson/1142775759>)

Henderson, D., et al., Taylor & Francis, 2023

## Understanding stigma in autism: A narrative review and theoretical model

(<https://doi.org/10.1089/aut.2021.0005>)

Turnock, A., et al., *Autism in Adulthood*, 2022

## Applications of identity-based theories to understand the impact of stigma and camouflaging on mental health outcomes for autistic people

(<https://doi.org/10.3389/fpsy.2023.1243657>)

Rivera, R. A., & Bennetto, L., *Frontiers in Psychiatry*, 2023

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