The Many Masks of the Autism Masking Debate

by

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Angel Sawka, a 21-year-old junior at Purchase College, has been diagnosed with autism, attention deficit hyperactivity disorder (ADHD) and anxiety. Sawka, who uses gender-neutral pronouns, sometimes has urges to say or do things that make others uncomfortable.

“I always say random and weird stuff, like something that I would think it was normal,” they said.

“People would look at me like I killed a cat or something… Or sometimes I do something that my brain would urge me to do and I'd have people say, ‘what are you doing?’”

‘Stimming’ to Self-Sooth

According to the World Health Organization (WHO), autism spectrum disorders (ASDs) are defined as “a diverse group of conditions characterized by some degree of difficulty with social interaction and communication.” There is also some degree of “atypical patterns of activities and behaviors,” which may include restrictive interests or repetitive behaviors. Some may also have sensory issues or challenges in executive functioning.

The WHO says that worldwide, an estimated 1 in 100 people have autism. The potential challenges that can come from autism vary from person to person and no experiences are universal. Someone may experience more frequent social challenges but less frequent executive functioning challenges, and vice versa.

To cope, some may turn to self-soothing behaviors known as “stimming.” Depending on the person, they may stim verbally, non-verbally or both. A few examples of verbal stims may

include making noises like humming or repeating certain words, whereas non-verbal stims may include rocking back and forth or snapping one's fingers.

Sawka is aware that stimming can be uncomfortable for those around them and sometimes will choose to tamp their impulse.

This repression is just one of the many ways people with ASD may engage in what the autism community calls "masking." Also called "camouflaging," masking may allow those on the spectrum to attain and hold jobs, attend school/college, and interact with those around them. But it comes at a cost.

"I would define masking as the hiding or compensation for autistic characteristics during social interactions," said Dr. Laura Hull, an evidence-based intervention (EBI) early career fellow at the University of Bristol Medical School in the United Kingdom. One of her particular research interests are the topic of masking/camouflaging in autism.

In 2017, Hull helped publish a study called "Putting on my Best Normal": Social Camouflaging in Adults with Autism Spectrum Conditions.

The study particularly wanted to address the masking process from the perspective of the participants. It also aimed to find their potential motivations to mask and any consequences they have felt from masking. They had 92 participants answer an online questionnaire about how they cope in social situations, in which the seven common responses were grouped in "themes." All of them said they mask their autism, except for six people.

There were two common themes reported which addressed the masking process. It is worth noting that the themes here aim to make a distinction between what defines "camouflaging" and "masking." However, "camouflaging" is the terminology primarily used in the 2017 study.

"At the time, 'masking' hadn't really been used very much and 'camouflaging' was more common in research. I asked participants in that study what they felt the best term to use was and more people said 'camouflaging' than anything else. However, I think that has probably changed now and more autistic people (although not all) prefer 'masking' to describe this phenomenon," said Hull.

Some people in the autism community instead refer to ASD as autism spectrum condition (ASC) because of the negative connotation that the word "disorder" can bring. This is done in Hull's study.

Seventy-six participants said they were "hiding behind what [they] want people to see." This is referred to as the "masking" in the study. "Respondents described attempting to minimize their self-soothing or 'stimming' behaviors, and their responses to sensory overstimulation, in order to make their condition less obvious to others. These techniques included using objects as 'props' to meet sensory needs in a subtle way, and giving themselves regular excuses to leave overstimulating environments and calm down." People who engage in this activity "emphasize a distinction between the respondent's 'true' or 'automatic' behaviors, and what they present to the rest of the world."

A Day in the Life

Sawka was not involved or previously aware of such a study existing, but relates to this. They recall an example on a Monday morning following Thanksgiving weekend. On breaks, Sawka lives in upstate New York with their family, which includes two sisters who also go to Purchase College. The commute is over two hours.

Sawka would use this day to take conscious note of how they experienced masking.

They left at 7 a.m., and had to beat traffic in order to make a 10:30 class. Sawka felt at least some desire to mask but would decide to not act on them. They say the decision was easy. “Whenever I make noise, since it's such a tight, compact place, everyone's able to hear it. I didn't want to startle or distract the one driving,” they said.

They say that apps on their phone helps reduce temptation. This includes video watching platforms like YouTube as well as games like Gardenscapes and Candy Crush. “They kind of make me not stim as much, especially with the music… When I’m playing a game, I’m not thinking about the other thing. My mind tends to drift off.”

Sawka would arrive to campus at 10 a.m., in time to make class.

Seventy-one participants said they wanted “to exceed what nature has given.” This is referred to as the “camouflaging” in the study. It means “developing explicit strategies to meet the social and communication gaps resulting from an individual’s ASC.”

“Explicit, compensatory strategies were reported by many respondents as a vital way to improve non-verbal communication with others… Respondents often described these

techniques as ‘rules’ or expectations from others that had to be met, even if they themselves felt these rules were not necessary.” They included “forcing and maintaining appropriate eye contact” and “an effort to display facial expressions of emotion or interest, even if they didn’t feel this inside.”

People in the study said applying these rules “required intensive monitoring of the way they presented themselves, in order to ensure they were being performed as correctly as possible.”

‘Very Easily Overstimulated’

“I come into contact with lots of business people,” said Olivia Bowyer in an interview over Reddit, a 24-year-old autistic person with ADHD and anxiety. She lives in the United Kingdom and works as a receptionist at Regus, a company which provides client-based office space. “It’s one of the times in life I have to more consciously mask because I know I need to come off as professional. So, no stimming in front of people, keeping conversation topics work appropriate, etc.”

Bowyer documented in diary her experiences masking at work on a Wednesday in January. She has sensory issues. “I am sensitive to quite a bit, like loud/sudden/repetitive sounds, light, taste, texture, etc.. Too much to go into detail, but basically I’m very easily overstimulated,” she said. Bowyer finds herself masking throughout the day.

At 9:45 a.m., she wrote, “I have to make sure if I need to stim, I can do it in a discreet way, like play with the buttons on my cardigan. Whereas if I wasn’t masking I would be shaking my hands about or wriggling my fingers about.”

At 10:30 a.m., she wrote, “I have to remind myself every now and again to make sure I am presenting myself professionally… I have to make mental checks to make sure I’m sitting in the desk chair properly. I would impulsively sit with my legs up on the seat but I know I should have my feet on the floor.”

However, there are instances where she might feel comfortable enough to unmask at work. “I find that when I’m in a more private place like the toilets or if I’m in an office alone, I start stimming normally without even thinking.”

There were two reported common themes for what exactly motivated people to mask in the first place.

Sixty-three participants said they “want to know and be known.” Like anyone else, people who mask have some desire for social connections. “Many respondents wanted to be accepted by others and be able to socialize, but recognized that they lacked the skills needed to make small talk, interact comfortably with strangers, and relax in social situations. This limited their ability to get to know people better.”

In addition, “this was particularly the case when describing their experiences in childhood and adolescence; respondents often reported that relations with others improved as they got older and were better able to camouflage their ASC.”

‘Hide in Plain Sight’

“I started mildly masking very early as a child, then went through middle school fully masked,” said Eden Marhold on an interview over Reddit, an 18-year-old who lives in England.

“Throughout middle school, some things I could mask better than others, for example I’d restrain myself from talking too much or saying my honest opinions. I forced eye contact, voice intonation and facial expressions. I’d bottle up sensory issues, ignore my accommodation needs, learn how to turn meltdowns into less disruptive shutdowns etc.”

Seventy-four participants in the study reported they “hide in plain sight,” which the study calls “assimilation."

“Respondents described wanting to camouflage in order to ‘blend in with the normals’. Most respondents reported a social expectation from the general population that individuals with ASC need to change in order to be accepted by others. Respondents’ social and communication difficulties, and their unique behaviors and interests, meant that they stood out from the crowd during social situations.”

“I used to be afraid of bullying because at this point in life I had a good understanding of how different I always was from everyone around me, both kids my age and adults. I’d mirror the behavior of my peers to fit in. I pretended to be extroverted and interested in others, to the point many people believed I was highly emotional and empathetic,” said Marhold.

As for the potential consequences of masking, 72 reported they “fall to pieces.” People often call this “burnout” in the autism community.

“Camouflaging was frequently described as being mentally, physically, and emotionally draining; requiring intensive concentration, self-control, and management of discomfort. The longer a camouflaging session continued, the harder it became to maintain the intended level of camouflaging.” In addition, “many respondents reported needing time to recover after

camouflaging, where they could be alone and release all of the behaviors they had been suppressing."

This recovery affects Sawka in between classes. "When I have time to myself, I kind of just release all that energy, and then I have to build it back up again and go back to another class," said Sawka, who says breaks are useful "to be able to get through the day more efficiently."

Forty-two said that they mask because "people have a stereotyped view [of autism]." This could be both positive and negative. "Many respondents felt that, because their camouflaging changed the way they presented themselves to others, they did not meet the stereotype of 'an autistic person' when they camouflaged."

The potential benefit of this is that they can be perceived as 'normal' because of their presentation, if done well. "By demonstrating good social skills and educating others about their conditions, respondents hoped to change the public perception of autism and make others more understanding."

However, when telling other people about their autism diagnosis, they may not be taken seriously. "[Seven] female respondents suggested that others were surprised that they had an ASC, since they differed so much from the public perception of an ASC man with high math skills, poor eye contact, and uncommon interests."

"Reaching the acceptance stage can feel very invalidating. I'm still learning how to argue against comments such as 'you don't look autistic' and 'you're using autism as an excuse' etc.," said Marhold, who does not identify as female.

Forty-nine people would say “I’m not my true self.” This means they are too used to masking to know what it’s like to be one’s true self. “This was often regretted by the respondents, who wanted to be happy as they were, but felt that the pressures of the typical social world meant this was not possible.”

“I’d switch my personality depending on who I interacted with as if I was an actor working 24/7. I remember having many identity crises because I couldn’t differentiate the real me from the masks, to the point I questioned if I had antisocial personality disorder many times. I felt like I was lying and manipulating everyone to find me likeable, even though it was an instinct to keep myself safe,” said Marhold.

“Because masking is such a subconscious part of myself, it’s really hard to know when I am truly unmasking. Is it when I’m around my friends, whom I feel comfortable around and truly partake in the conversation? Is it around my boyfriend, when I feel I am able to stim and be silly? Or is the only time I am truly unmasked when I am completely alone, free to act however I want without worrying what others will think? I honestly don’t know who I am at the core,” said Bowyer.

“The themes that were identified in this study have helped give me an overview of why people mask, what they do when they are masking, and the impact it can have on them. These themes contain some nuance, representing the different types of experiences people can have (e.g. using very conscious strategies versus masking automatically), even though they don’t perfectly represent everyone’s experience,” said Hull.

Perks vs. Pain

Morénike Gina Onaiwu, Ph.D., an autistic self-advocate who founded Advocacy Without Borders, a non-profit organization that advocates for inclusive spaces for those who are neurodiverse, called masking a “critical topic.”

“I think [masking] is something we need to talk about more,” she said. “I think it’s such a critical topic for [the] community for all across the age, the lifestyle they have from, youth to adults. It’s a huge issue and so I'm just glad to see it get more concentration and more attention.”

For many people with autism, the decision to mask is contentious. Are the potential perks worth the added pain that comes from masking?

Autism was first documented in psychology over 100 years ago. The earliest usage of the word autism began with the contributions of Swiss psychiatrist Eugen Bleuler in 1911. A few years earlier, in 1908, he had already coined the term “schizophrenia,” the focus of research. In a 1911 paper called Dementia Praecox or the Group of Schizophrenias, he created a diagnostic criterion for different levels of schizophrenia. They were “abnormal associations, autistic behavior and thinking, abnormal affect and ambivalence.”

He coined “autism” as a term to describe schizophrenia patients who were the most withdrawn from reality. The etymology of autism derives from the Greek prefix “auto,” which means the self and the Greek suffix “ismos,” which means a state of being. This roughly translates to a state of being in oneself.

For the next few decades, multiple researchers in a number of countries would research and find ways to expand on Buehler’s concept.

In 1925, Russian child psychiatrist Grunya Sukhareva published a paper called Die Schizoiden Psychopathien im Kindesalter. It described the first clinical accounts of autism, which in turn, narrowed the definition of autism. She spent over a whole year studying six boys who Bleuler would consider to be "autistic." Sukhareva was eventually able to pinpoint the specific challenges encountered by people with autism, such as difficulty in showing specific interest in other people, a preference for routine/repetition and sensory sensitivities.

As she studied the boys more, she saw that autism can come with potential strengths as well. Each boy in the study had either a talent or particular interest. One was good at the violin but could not socialize well, while another had an interest in philosophical conversation but could not recognize faces well.

Austrian-American child psychiatrist Leo Kanner published a paper in 1943 called Autistic Disturbances of Affective Contact. He had a case study of 11 kids and dove into their family and environmental situations as a possible influence for their behaviors.

Kanner coined the term "early infantile autism" after establishing a set of patterns that distinguished autism from schizophrenia. He found an "inability to relate themselves in the ordinary way to people and situations from the very beginning of life." Schizophrenia instead usually has an onset during adolescence or early adulthood.

However, masking is only within the past decade becoming an area of research. Hull says "several people started researching it" around 2015-2017, but acknowledges that the topic of masking has been raised in the autism community before that.

Dr. Amy Pearson, a senior lecturer in psychology for the University of Sunderland in the United Kingdom, helped publish a 2021 study called Understanding the Narrative of Stigma and the Illusion of Choice. Her study aimed to figure out what was missing in masking research.

One of the topics it argues is that "there has been minimal focus on the role that the social sphere plays in the development and maintenance of masking. A person's identity is shaped by myriad factors, not least the social environment that they inhabit." She has an upcoming book, "Autistic Masking: Understanding Identity Management and the Role of Stigma," which she says will explore this.

Pearson also acknowledges the need for more intersectional research towards masking, specifically when someone has multiple diagnoses along with autism. According to a 2011 study, people with autism are more likely to have co-occurring conditions, such as ADHD and anxiety.

"I think in general a transdiagnostic, neurominority approach can help us to understand how masking arises as opposed to framing through a purely 'fitting in' lens," she said. "Masking is a stigma response, and these responses are well documented in stigmatized communities -- we need more research which merges these areas."

Sawka, the Purchase junior, acknowledges the relationship between ADHD and anxiety with masking. They co-occur with some executive functioning challenges with inhibitory control, or overthinking, as well as sensory issues. This can affect the classroom experience.

Anxiety and the Urge to Mask

On their return from Thanksgiving break, there was little time to decompress before their first class. “I didn't pack everything, all because I had class and I couldn't really be late, especially after Thanksgiving break,” they said. Sawka’s first class of the day, “Finance for the Arts,” was in the Fort Awesome dorm building.

“Whenever I read stuff on the board… information goes from one ear out the other in the matter of five seconds. I feel like everything I hear is kind of like fuzzy,” they said. “I think about stuff all the time from the past and I just kind of daydream a lot too in class. So, it's just easy for me to get distracted.”

“Finance for the Arts” has about 20 to 25 students, which Sawka says can influence the urge to mask as well as their anxiety. “The more people, the more I want to mask, but at the same time, the less people, the more I want to mask. It kind of goes hand in hand. When there is more people, I’m more likely to get a weird look,” they said.

Sawka uses their phone to cope with this. “I did spend some of that time playing a game,” Sawka said. “So, I wasn't paying attention for the most part.”

Once the class ended at noon, Sawka said they felt “drained.” “The fact that I sat for three hours, and then sat for another hour and a half, yikes,” they said.

Sawka’s next class, “Making a Case for the Arts,” would not start until 2:30 p.m. in the Humanities Building. However, they first had to finish moving their things before they could finally have time to be alone. “After around one, that's when I was like, ‘yeah, I suppose I could just chill and watch YouTube,’” said Sawka.

“Since this is the smallest class I’m in, there's a more likely chance I'll get picked to answer questions and/or give the class my thoughts on certain ideas discussed in class. Also, my professor typically tries to bring back my attention if I end up spacing out for any reason, which is a good thing, but also kind of takes an effect of ‘oh man, I have to focus,’” said Sawka.

Sawka says that masking these challenges affects them significantly: “six on a scale of one to 10. It’s not bad, but not good either.”

Bowyer masks both her autism and ADHD at work. For her first diary entry, she noticed she already had begun masking upon walking in to her job.

“There were already people waiting when I arrived at 8:30, so I had no time to get myself in the ‘work frame of mind’ which never sets me up well for the day,” she wrote at 9:30 a.m.

Bowyer says “executive dysfunction is a major issue” for her and she sometimes would “spend hours doing nothing because [she] can’t bring [herself] to spend 10 minutes washing up.” Task transitioning can indeed be an executive functioning challenge for some autistic people. She says that her ADHD is a reason for that as well as her autism.

Some autistic people may prefer predictability in certain situations, and for them, unpredictability can sometimes pose as a challenge. For Bowyer, this is compounded by her anxiety.

“We have a big client in today and most people don’t know where they’re going,” wrote Bowyer at 9:30 a.m. “We have a list of people who are coming in and where to take them --

that works well for me but there have been a few people not on the list. I have had to try and come across as professional as possible, when inside I'm panicking because I don't want to send them to the wrong place."

At noon, she wrote, "I spent most of the day sitting next to the security guard for the building. I get on well with him and definitely feel like I can slightly unmask around him." She acknowledged this was another situation where she was both anxious and masking.

"There are long periods of silence. I know it's normal to sit next to someone and not speak but I still always feel weird sitting in silence and have to stop myself from making pointless small talk. He will also occasionally start watching videos on his phone quite loudly, which doesn't send me into full sensory overload but I definitely don't like it and it makes me feel a bit icky. I'm too polite/socially anxious to ask him to turn it down.

"Sometimes I slip up and I get the vibe I've said something a bit weird or inappropriate and then that gives me anxiety, which also contributes to the exhaustion at the end of the day," said Bowyer.

At 3:30 p.m., she wrote, "I usually find myself getting quite tired at this point in the day, so I find small talk especially difficult. I won't really seek out a conversation with someone unless they initiate it and I'm not as eager to continue the conversation if they do."

At 5 p.m., Bowyer is almost done with work, and wrote how the day "hasn't been too difficult." However, she said, "This doesn't mean that I haven't been masking all day though… even days when I don't do much work but I've been talking to people, I come home from work absolutely shattered."

Despite all of this, Bowyer is appreciative for the type of work she has. “Overall, I’m grateful I have a job that isn’t too hard because I know there’s autistic people out there who struggle to get a job in the first place,” she said.

Yet Bowyer acknowledges that her job is not perfect and could be more autism-friendly. “Sometimes I do wish I had a job where I just got to work with a core team and didn’t have to interact with people outside of that so I could get to know and relax around,” she said.

According to two national longitudinal studies, only 58% of those with an ASD in their early 20’s is employed. Onaiwu believes that part of this is due to how a lot of traditional jobs “encourage” masking.

“You need to mask the interview, you need to mask throughout your performance and interactions at work, and I think that isn't something that's sustainable over the long term. You spend a lot of your day at work… The intellectual and emotional labor that is required to mask and still perform, I think it causes a lot of us to break,” said Onaiwu.

They “think for some autistic people, nontraditional employment or entrepreneurship isn't a bad option.” However, particularly in the United States, Onaiwu said they “feel like sometimes people don't really have much of a choice, because a lot of the jobs that are viable, have opportunities for advancement or have salary that's pretty competitive, are places or environments where you would need to mask even if you don't want to, to survive.”

Gender Influences

Hull helped conduct a study in 2019 called Gender differences in Self-Reported Camouflaging In Autistic and Nonautistic Adults. It argues there is a “female” phenotype of autism, such as being more likely to internalize conditions like anxiety and higher social pressures, which makes them more likely to mask than men.

The study found there was generally a “greater extent of camouflaging of the autistic traits they do have, perhaps because of greater social expectations for females than males. Autistic women may experience unique and more extreme pressures than either autistic men or typically developing women, in part because of the intersection of their identities as neurodivergent and female, which may lead to differences in behavioral expression of autistic characteristics compared to the ‘typical’ male presentation.”

“I am less likely to unmask because I feel I am already not taken as seriously as a woman, and people seeing the ‘real’ autistic me will make them infantilize me and treat me even less seriously,” said Bowyer.

A separate 2017 study estimates the male-to-female ratio of autism to be 4:1 to 3:1. It was long assumed to be closer to 4:1 than 3:1, however the study claims "it is closer to 3:1” and “there appears to be a diagnostic gender bias, meaning that girls who meet criteria for ASD are at disproportionate risk of not receiving a clinical diagnosis.”

Hull’s study acknowledges that “camouflaging of autistic traits may be more predominant in autistic females and may partially account for the missed and later diagnosis of autism found for many females.”

"Without a doubt, my autism wasn't picked up on until I was an adult because I am a girl," said Bowyer, who was diagnosed at 19. "Because I was diagnosed as autistic as an adult, I find it difficult to know whether or not I am masking, even five years after diagnosis… I think that the longer you go without a diagnosis, the more masking becomes a subconscious part of life."

Pearson's study, however, specifically challenges Hull's argument that masking should be gendered. "The idea of a female autism phenotype also fails to recognize the large number of autistic people who are outside of the gender binary, potentially creating further barriers to diagnosis and support and the perpetuation of a stigmatizing narrative," she said.

According to a 2020 study published in the journal Nature, there is a higher likelihood among those with autism to also be transgender. Pearson says she "has already done some work in this area" in regards to how it affects masking and "hopefully will find some time to write the findings soon." She plans to present them at the International Society for Autism Research (INSAR) annual meeting in June.

Marhold and Sawka, who are both non-binary, attest to experiencing hiding their gender identities while simultaneously masking their autism.

"It felt like I was performing a persona on a much deeper level than just masking. I was not only trying to convince my surroundings that I'm someone I'm not, but also myself," said Marhold.

"I remember at one point, [my mother] cut my hair somewhat short," said Sawka, who was raised a girl. They wanted their hair even shorter than it was to explore their gender

identity. “During junior year, I decided ‘hey, I’m probably going to cut my hair.’ I did that, but everyone got mad at me for ruining the haircut that my mom gave me…”

Sawka is a quadruplet and grew up with three sisters. Sawka is the only one out of them who is gender-diverse and one of two who have autism. “I always felt like the black sheep in my family. I always felt like ‘how would I socialize with these people; they think I'm weird.’ So, I'm usually involved in my own type of stuff, or I just sit there in the background doing really nothing at all. Or sometimes when I do manage to bring technology, especially like Christmas parties, I just stay on technology until we have to leave,” they said.

Hull sees this as well. “Much of the research has focused on binary gender when looking at masking, and although we know that non-binary people (as a broad group) mask highly, we don’t know much more about how gender diversity interacts with autistic masking,” she said.

Pearson’s study acknowledges on the flip side that “it is important to recognize the different ways in which autism might present in intersection with other aspects of a person’s identity and socialization.”

According to Hull’s 2017 study, “several respondents felt camouflaging was only necessary for the initial stages of a friendship or relationship; once a connection was established, the respondent felt more comfortable showing their ‘true’ ASC characteristics.”

“I want to be myself around my close friends but I don’t mind masking around colleagues/acquaintances because I would rather mask than deal with the embarrassment that people think I’m being ‘weird,’” said Bowyer.

However, for other people, it takes a lot more trust. According to Sawka, their sister, Anna, is “the only person they feel like they can truly unmask around.”

“It makes me feel cool and trusted,” said Anna, who also has diagnosed autism. “We kind of get each other, so it’s not even weird. We’ve done it since birth.”

Marhold instead has gone the opposite route of Bowyer and Sawka and put masking behind them. “I’m no longer in contact with the people I used to mask around, and nowadays I’m unmasked as a default around everyone I talk to,” they said.

Onaiwu acknowledges “there are some individuals who feel like they can be who they are in most settings, for whatever reason.” However, they think that “generally, intentionally unmasking does require more trust… There's definitely a sizable amount of people who do feel cautious and want to observe and kind of hold back and won't just automatically unmask until you have a sense of security in that setting,” said Onaiwu.

There appears to be a common theme that people think could help make that more of a reality in the future: bringing awareness of masking to those who do not experience it first-hand.

“I think that when you have somebody that understands, even if they don’t fully get it, but they are accepting of the way that you are and accommodating, I think that does go a long way. That does make you feel like ‘who I am is not problematic’ and it makes you more likely to kind of lean into being yourself and to embrace traits about yourself that might be different. I think that is interesting,” said Onaiwu.

From a researcher's perspective, Hull agrees on this point. "I hope that with increasing education of neurotypical people, people with autism will feel that they don't have to mask in order to avoid being treated differently, or experiencing stigma as a result of being autistic," she said.

"I'd be willing to let allistic people be educated on when and how autistic people resort to the process, whether in private or public," she said, using the term "allistic" to refer to those not on the autism spectrum instead of the judgmental term "normal." "They'd be able to at least understand the way an autistic mind works differently than an allistic one from a distance, they'd know what to do to in situations which involves their autistic friend shutting down, and it would also help those assisting autistic children to better their knowledge to regulate their emotions, when necessary," said Sawka.

Allistic Allies

Some of those without diagnosed autism are already bringing it on themselves to do their best to make those with autism more comfortable. Bella Kaloz, a 20-year-old environmental science and policy major at Marist College, is one of them.

"Every time my friends with ADHD, autism or other disorders come together we always have a good time and can be weird and goofy with each other without judgment," said Kaloz, who has ADHD. "It's pretty easy for me to create a safe space with people who face similar difficulties that I do… Helping my friends unmask isn't something I actively go out and do -- it's something we all feel comfortable doing together unprompted."

“My cousin is autistic, and I try to act how I do with them like with everyone else,” said Katherine Larca, a 22-year-old barista who lives in eastern Pennsylvania. She does not have diagnosed autism either.

“Masking can be useful and ensure safety. It's an important part of many autistic people’s experiences and many lives depend on it. At the same time, it shouldn’t be encouraged in order to satisfy allistics and their comfort, for those that have the privilege of living in a more accepting and open-minded society.”

Bowyer and Hull agree.

“It’s honestly really complex, I think. People shouldn’t *have* to mask but it does help a lot of autistic people fit in and it’s not necessarily a bad thing,” said Bowyer. “I really think it depends on the person and their own opinion; it shouldn’t be like ‘autistic people should/should not mask.’ If someone genuinely wants to mask, and they’re happy doing that then that’s up to them.”

“Some autistic people may still want to mask, if they feel it is easier in certain situations (e.g., masking certain stims if these conflict with other autistic people’s sensory needs) or helps them achieve goals, but I hope that they will feel this is a choice rather than an expectation, and that they can mask on their own terms, if at all,” said Hull.

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Primary Source List

Angel Sawka, main source, 11/10/22, in-person

Overview questions (personal history with masking, attitudes towards masking, how autism diagnosis has impacted life, etc.)

(518) 955-1498, angelsawka8@gmail.com

Angel Sawka, main source, 12/3/22, in-person

Opening anecdote

(518) 955-1498, angelsawka8@gmail.com

Angel Sawka, main source, 1/6/23, phone call

Filling holes in reporting up to that point (specifically finding out how the phone subdues temptation to mask and finding out more about what classes feel like)

(518) 955-1498, angelsawka8@gmail.com

Angel Sawka, main source, 4/11/23, in-person

Gender and masking

(518) 955-1498, angelsawka8@gmail.com

Olivia Bowyer, main source, 10/30/22 – 11/1/22, over Reddit direct messages

Overview questions

u/Livvygrace246, oliviabowyer98@gmail.com

Olivia Bowyer, main source, 1/16/23 – 1/18/23, over Reddit direct messages

Workplace anecdote

u/Livvygrace246, oliviabowyer98@gmail.com

Olivia Bowyer, main source, 4/4/23 – 4/11/23, over Reddit direct messages

Gender and masking, knowing what it is like to be one's "true self"

u/Livvygrace246, oliviabowyer98@gmail.com

Eden Marhold, main source, 2/25/23 – 2/28/23, over Reddit direct messages

Overview questions

u/_-eeden-_, eden.marhold@gmail.com

Eden Marhold, main source, 4/4/23 – 4/6/23, over Reddit direct messages

Gender and masking, knowing what it is like to be one's "true self"

u/_-eeden-_, eden.marhold@gmail.com

Dr. Laura Hull, masking expert and an evidence-based intervention (EBI) early career fellow at the University of Bristol Medical School in the United Kingdom, 2/13/23-2/14/23, over email

Addressing things in the first article I mention that I did not quite understand.

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Dr. Laura Hull, masking expert and an evidence-based intervention (EBI) early career fellow at the University of Bristol Medical School in the United Kingdom, 4/6/23-4/12/23, over email

Asking her about current holes in masking research

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Dr. Amy Pearson, masking expert and a Senior Lecturer in Psychology for the University of Sunderland in the United Kingdom, 4/11/23, over email

Asking her about current holes in masking research

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Anna Sawka, sister of Angel, 4/18/23, in-person

What it is like to have Angel close enough with you to the point they completely unmask.

Annabella.sawka@purchase.edu

Bella Kaloz, person without autism who helps foster environments without masking, 4/7/23, over text

See above

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Katherine Larca, person without autism who helps foster environments without masking, 4/12/23, in-person

See above

(845) 324-5444, katelarca@gmail.com

Morénike Gina Onaiwu, PhD, founder and principal operator of Advocacy Without Borders and autism rights activist, 4/20/23, over Zoom

Perspective on certain points as an autism rights activist

staff@AdvocacyWithoutBorders.org (staff member)

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