

## OPINION, VIEWPOINT

# Measuring alexithymia in autistic people

BY KATHERINE GOTHAM, ZACHARY J. WILLIAMS

24 AUGUST 2021

*Listen to this story:*<https://www.spectrumnews.org/wp-content/uploads/2021/08/audio-c06d6f67-017a-4ef6-bcc8-f532ea960629-encodings.mp3>

People vary greatly in their ability to identify and describe the emotions they feel every day. While many people can easily tell when they are happy, sad, angry or frightened, others have great difficulty making sense of their emotional states or describing them to others. People with such challenges are said to have high levels of **'alexithymia'**, a personality trait that literally translates to "no words for emotions." In addition to problems identifying and describing feelings, people with high alexithymia prefer to focus their thoughts on things they can see or touch, rather than their own or others' emotional experiences, a cognitive style that has been termed 'externally oriented thinking.'

Many people on the autism spectrum are familiar with alexithymia, even if they haven't heard the term. Studies estimate that **nearly half of autistic adults** exceed clinical cutoffs for 'high alexithymia,' compared with just 5 to 10 percent of the general population. Among autistic people, higher levels of alexithymia predict more significant social communication difficulties, as well as **mental health challenges such as anxiety**. Additionally, research suggests that certain characteristics commonly associated with autism (such as **empathy differences and difficulty recognizing emotional facial expressions**) may actually result from alexithymia rather than autism itself.

Despite the growing interest in alexithymia in autism research, few studies have looked at whether the tools commonly used to measure this trait work reliably in autistic populations. Even the most popular metric, the **20-item Toronto Alexithymia Scale (TAS-20)**, is routinely used despite that researchers don't know if it measures the same underlying construct in autistic and non-autistic people. Without this information, we cannot be sure that score differences on the TAS-20 or other measures reflect true differences in alexithymia rather than differences in how autistic and non-autistic people **interpret questionnaire items**.

To fill this gap, our team undertook the **first large-scale validation study of the TAS-20** in a sample of autistic adults. We found that many of its questions were poor indicators of alexithymia in autistic adults, which led us to develop a new scoring method, the general alexithymia factor score, or GAFS-8. Owing to a **copyright issue**, we could not name our new method after the TAS-20 instrument, as we did in an initial, retracted version of our paper. But the GAFS-8 score draws on eight of the TAS-20 questions that appear to work well for both autistic and non-autistic individuals. Our research also calls into question the degree to which alexithymia is related to certain mental health issues in people on the autism spectrum.

## **Eight is enough:**

For our study, published this month in *Molecular Autism*, we used the **SPARK participant pool** to recruit a sample of 743 verbally fluent autistic adults. (SPARK is funded by the Simons Foundation, *Spectrum*'s parent organization.) The participants, aged 18 to 45, all completed a set of questionnaires, including the TAS-20. This large dataset allowed us to use statistical models that estimate the degree to which autistic adults' levels of alexithymia were responsible for their scores on each of the 20 questions.

The TAS-20 has three subscales: sets of questions that measure difficulty identifying emotions, difficulty describing emotions, and externally oriented thinking. We found little support for items that assessed this last category. Questions such as "*I prefer to analyze problems rather than just describe them*" and "*Being in touch with emotions is essential*" did not correlate well with model-based estimates of 'general alexithymia' in our sample of autistic adults. These questions and several others appeared to contribute little more than measurement error.

This discovery prompted our efforts to identify a subset of eight TAS-20 questions that could reliably assess alexithymia in individuals on the autism spectrum. Using statistical methods, we validated the GAFS-8 score in both autistic and non-autistic adults, providing the first evidence of an alexithymia score that measures the same underlying construct in both populations.

We further examined correlations between GAFS-8 scores and other characteristics of interest, such as autistic traits, quality of life and mental health problems such as depression and anxiety. As expected, the GAFS-8 score correlated positively with autistic traits and mental health problems, additionally predicting a reduced quality of life.

Going one step further, we reexamined these correlations while accounting for levels of **neuroticism**, or the degree to which a person experiences distress and negative moods in their daily life. Unlike some other alexithymia measures, the TAS-20 measures **both alexithymia and neuroticism**, according to one 2020 paper, making it difficult to know which of the two personality traits is contributing to outcomes of interest.

When we statistically controlled for neuroticism in our SPARK sample, we found that alexithymia as

measured by GAFS-8 still strongly predicted autistic traits and quality of life but the associations between GAFS-8 scores and mental health symptoms became much smaller and were, in some cases, no longer meaningful. Further research is needed to determine whether alexithymia does in fact predict the development of mental health problems in autistic adults or whether co-occurring neuroticism — **an established predictor of poor mental health** — is responsible.

To facilitate the use of the GAFS-8 in research and clinical practice, we have created a free and easy-to-use **online score calculator**. It allows for the calculation of population-normed GAFS-8 scores as well as individual score reports that classify a given person as having ‘high alexithymia’ or not. We hope that this measure can begin to replace the TAS-20 total scores in studies that compare alexithymia across autistic and non-autistic groups.

Because the GAFS-8 is confounded by neuroticism and lacks items assessing the ‘externally oriented thinking’ domain of alexithymia, alternative measures, such as the **Perth Alexithymia Questionnaire** and the **Toronto Structured Interview for Alexithymia**, may prove more appropriate for use in autistic people — although research is needed to validate these tools in this group. In addition, because our SPARK sample was disproportionately white, female, well-educated and diagnosed with autism in adulthood, it would also be valuable to test the GAFS-8 in autistic people with different demographics.

Our study is part of a broader movement to determine if widely used psychological tools work effectively in people with autism or if new or revised tools are needed. In other recent work, for example, we showed that the Beck Depression Inventory-II is a valid measure of **self-reported depressive symptoms** in autistic adults. In the case of childhood anxiety, by contrast, other researchers found that a **new assessment** was needed for children on the spectrum. We hope that by demonstrating the importance of measure development and validation, we can inspire other autism researchers to take part in this process and critically examine the measurement tools that our science is built upon.

**Cite this article:** <https://doi.org/10.53053/FWEH2679>