The study by Szatmari et al.1 moves away from investigating negative outcomes for people with autism spectrum disorder (ASD), instead focusing on what “doing well” looks like and describing its prevalence and contributing factors. The authors defined doing well as proficiency (performance on standardized measures consistent with those without ASD) and/or growth (improvement from early childhood) across 5 domains known to be areas of difficulty in ASD (i.e., socialization, communication, independent living skills, internalizing symptoms, and externalizing behaviors), hence creating 10 possible categories for doing well. This was explored in a population-derived sample of children with early ASD diagnoses followed longitudinally. The present findings compare status in early childhood with performance in mid-to-late childhood pooled across 2 measurement time points. The key finding was that 80% of this sample were doing well at follow-up in at least 1 domain (by the proficiency and/or growth definition), with 23% doing well in 4 or 5 domains. Notably, early childhood factors associated with doing well were primarily within the same domain, suggesting that those doing well in early childhood are most likely to continue to do so in middle and/or late childhood. One important exception was the finding that better family functioning was associated with growth (i.e., improvement) in the internalizing symptom domain.

On initial reading, the results suggest a positive outlook for children diagnosed with ASD in early childhood. However, the proportion not doing well by either definition ranged from 44.5% for externalizing disorders to 74.3% for socialization, highlighting that there is no place for complacency. It is also important to consider that middle childhood may be a time when strengths are most apparent in those with ASD. Clinical experience and evidence from research both suggest that the transition to high school and adolescence, with the added social, academic, and cognitive demands, often alongside changes in the child’s support systems, can be highly challenging for young people with ASD. Longitudinal studies following individuals further into adolescence and early adulthood indicate continued problems with and, in some cases, worsening mental health over this period. In the recent cohort study by McCauley et al.2 of young adults with ASD who had been followed from early childhood, it was found that symptoms of depression increased throughout adolescence, peaking in the early 20s. Having provided a working definition of doing well for this cohort, it will be important to see how this is borne out as these young people are followed-up over time. This highlights the power of the longitudinal design to understand outcomes in ASD, both at a population and individual level.

Despite this caveat about longer-term outcomes, the finding that 80% of this sample had at least 1 area of proficiency or growth has clear clinical implications and highlights the value of strength-based approaches in this population. There has been an increasing focus on both individualized and strength-based approaches to working with those with ASD. This is important because evidence suggests that such interventions are well received by those with autism and their parents and have been found to have a positive impact on a range of outcomes, including self-esteem, confidence, and the development of social relationships.3 Szatmari et al.1 show that proficiency and growth outcomes are at least partially independent from ASD severity. This suggests that regardless of where a child sits on the autism severity spectrum, improvements within domains are possible and that interventions may be successful despite low proficiency in nontargeted domains. However, it is unclear from the current study what interventions this sample has had over
the period between time points and what impact this may have had on the outcomes reported. This aside, these findings may also indicate that interventions could be built upon areas of individual strength to promote better outcomes even for those individuals who are struggling in most other areas.

One advantage of looking across a range of functional domains, as the authors have done in this study, is the ability to show which factors may be overlapping and which may stand apart as shared, or potentially individual, risk factors that can be targeted for intervention. It is interesting to note that there was little association between those doing well in adaptive functioning and in mental health measures, with longitudinal associations being almost exclusively within domains. This is consistent with data from other longitudinal studies, which suggest persistence (both in strengths and weaknesses) in both adaptive functioning and mental health symptoms throughout development. As the authors highlight, this type of study paves the way for more personalized approaches in which we can begin to estimate and track which individuals are most vulnerable to continuing difficulties or amenable to change over time. Therefore, the approach taken by Szatmari et al is an important one because by starting to define what doing well looks like over time it allows clinicians, policymakers, and (importantly) families to understand which domains remain most resistant to change. This informs future research to develop intervention approaches targeting potentially modifiable factors. For example, the proportion of those doing well through growth was highest for internalizing symptoms, suggesting this may be a more modifiable domain of functioning that could be targeted through early intervention. Indeed, while for most young people the severity of their autism is stable, we know that mental health can fluctuate, and is impacted more strongly by environmental factors.

This relates to another consideration, highlighted by the authors: the influence of contextual factors in doing well for those with ASD. Here the authors reported that family functioning was associated with growth in the internalizing symptoms domain. In terms of modifiable factors, environmental and family characteristics may arguably be the most amenable to change, but often are the most overlooked in autism research. Longitudinal studies that aim to use representative samples face both the challenge of capturing these effects using standardized measures but also accounting for their influence on study sampling and attrition. While the authors acknowledge a degree of attrition in the current study, it is important to consider what impact this has on the generalizability of the findings. We know that several family factors, such as financial problems, parent educational level, employment, and being a single parent are associated with attrition in longitudinal studies. It is important going forward to both understand how these factors contribute to doing well in those with ASD and consider how best to account for attrition statistically to avoid underestimating these effects.

The authors should be commended on their efforts to change the problem-focused narrative around outcomes in people with ASD to one that is both strength-based and lays the foundation for a shift toward a more individualized understanding of how best to support this population. Despite these findings, it is important to hold in mind that people with ASD, regardless of their individual strengths, commonly continue to experience high levels of difficulties with everyday living skills and mental health. Further longitudinal research is required that builds upon the work in this study to identify individualized and modifiable characteristics, as well as environmental factors, as targets for the development of treatments and early intervention.
REFERENCES


