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Erin Bulluss, Ph.D., and Abby Sesterka
Insights about Autism

AUTISM

When a Late Diagnosis of Autism Is Life-Changing

A diagnosis of autism in adulthood can change self-concept for the better.

Posted Jan 07, 2020



Source: Insights About Autism

Take a quick scroll through the right social media groups and you'll find countless individuals sharing their stories about receiving a late diagnosis of autism, or Autism Spectrum Disorder, as the condition appears in the DSM-5.¹ While the presentation of autism varies considerably between individuals, many of the narratives presented bear a

common theme: the experience of finally solving a lifelong riddle, of

understanding why there was always a feeling of being different, displaced, difficult.

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Indeed, a recent study explored the experiences of a number of late-diagnosed adults, who reported feeling alien and isolated, and who were aware of not fitting in (without understanding why) before they were identified as autistic.²

These themes are familiar to the authors of this article as late-diagnosed women. And, post-diagnosis, we understand that we are different; we are developmentally divergent, and we embrace our differences with a newfound understanding, insight, and clarity. But the feeling of being difficult is a different story. This is not inherent, and this is not autism. This stems from our experiences of being misunderstood as we were growing up, the unspoken feeling that something was different about us, without having the word “autism” to understand or articulate what that difference was.

Before our diagnoses, stories of our perceived recalcitrant behaviors were entrenched in our respective family repertoires of amusing and bemusing stories, like the time when Erin ruined a family trip to a theme park by wearing her darkest frown while riding the merry-go-round over and over and over again, or Abby’s “temper tantrums” that were frequent and unpredictable. In hindsight, and with the benefit of diagnosis, we and our families now recognize that these behaviors were not those of obstinate children, but of autistic children grappling with managing situations that were uncomfortable, unpredictable, or overwhelming.

Appearing difficult while living a difficult life: balancing self-preservation with the demands of adulthood

This notion of "being difficult" followed us into adulthood, which is not an uncommon experience for autistic women.³ We both work in areas that are high pressure, emotionally and cognitively demanding, and involve frequent

and inflexible deadlines. In such professional environments, down time becomes essential to recuperate for the week ahead. Taking time out is not self-centered, though it is often viewed as such. It is self-preservation.

Many activities that are just part of daily life for most people require hours, if not days, of recuperation time for us as autistic women. For example, attending a social event requires a substantial performative social interaction,⁴ resulting in “social hangovers” that can last for days and include extreme physical and mental exhaustion that impacts greatly on functioning.

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While many people are able to use their weekends for maintaining their household, their friendships, and their community connections, for autistic adults who have ongoing work or family demands, this often isn't possible without compromising mental or physical health. This is such a common experience among the autistic community that autistic advocate Maja Toudal developed the “[energy accounting method](#)”⁵ to help manage her energy levels while studying. This concept has since been co-opted by psychologist Tony Attwood, who presents and writes about energy accounting in the context of promoting mental health in autistic people.⁶

THE BASICS

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While scattered profiles (e.g., performing at high levels in professional realms but struggling with some day to day tasks) are a common feature of autism, and energy accounting is key in promoting well-being in autistic adults, it is frequently misinterpreted when put into practice. For example, an aversion to shopping in supermarkets may be viewed as laziness or shirking of chores,⁷ when it actually represents a very real struggle to tolerate the sensory

aspects of the environment while retaining sufficient executive function to carry out the core task of grocery shopping.

The choice to avoid environments that are cognitively demanding is a choice to preserve energy for other tasks. It is the choice to accept help, to do things differently; not because we are difficult, demanding, or disagreeable, but because we are autistic and have different strengths and limitations than non-autistic folk.⁸ We accept that this may be viewed negatively by those who don't understand us, our experiences, and our needs. Ultimately, it is not worth compromising our well-being just to avoid being seen as lazy or difficult by people who are judging us against neuro-normative standards.

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Reframing one's narrative: seeing through new eyes

While the path to diagnosis is hardly an easy one, for us, it provided the opportunity to re-examine our ways of doing, being, and thinking. This essentially led to a positive shift in self-concept, as we let go of maladaptive core beliefs about ourselves that were rooted in a lack of understanding of our own experience. In being diagnosed, and thus adopting an accurate framework to understand ourselves, we see traits that we previously thought to be difficult, anomalous, or onerous as simply part of our autistic identity.

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These traits are no longer alien and inexplicable but are now entirely understandable and acceptable when viewed through a lens of autism. This echoes research that explored experiences of late-diagnosed adults, in which the majority of participants had revisited aspects of their personal history and rewritten their personal narratives, resulting in positive outcomes.⁹

We both self-identified as autistic long before deciding to seek formal diagnoses, so we expected that the diagnostic process would simply be seeing what we already knew to be true inscribed on paper. As firm believers in the validity of self-identification by informed and self-reflective adults, we underestimated just how transformative the formal diagnostic process would be for us. Our lives have now been split into pre- and post-diagnosis; taking us from a place of confusion, frustration, and obfuscation to a place of understanding, self-acceptance, and radical authenticity.

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We now have an understanding of the framework that underpins our existence: we have come to accept our strengths and know that they are not diminished by our challenges; we now know how to exercise better self-care and are healthier and happier for it; we no longer waste energy trying to be successful neurotypicals and, instead, focus our efforts on thriving as our autistic selves.

Our late diagnosis signaled the start of a process of correcting inaccurate thoughts, beliefs, and underlying schemata that had developed over decades of our lives. We are not difficult or broken or failed; we are acceptably, adequately, appropriately autistic.

Autistic, not difficult

Our diagnosis allowed us a framework by which to break out the red pen and rewrite the narratives of our lives; to look back on and reprocess events through a lens of autism, to confidently strike out the word “difficult” and

proudly replace it with “autistic.”

- "I always asked for the same number of ice cubes in my drink because I am difficult autistic."
- "I feel overwhelmed at parties because I am difficult autistic."
- "I like to talk about topics that interest me rather than engage in small talk because I am difficult autistic."
- "I am disconcerted when there are unexpected changes in my environment because I am difficult autistic."
- "I need to know specific details in forward planning because I am difficult autistic."



Source: Unsplash/Ryan Morneo

With the reframing and deeper understanding that were facilitated by our diagnosis, we have come to conceptualize ourselves in a more positive light. We recognize now that it is not us who are difficult, but rather it is the onus of conforming to neuro-normative expectations throughout our lives that has been difficult for us.

We were fortunate to have formal and informal supports to assist us in this process, however, not everybody who receives a late diagnosis of autism has support available. Research indicates that some autistic adults do not experience a positive shift post-diagnosis,¹⁰ suggesting a need for accessible, autism-positive resources to guide late-diagnosed autistic adults in the process of reframing narratives. With an increasing number of autistic individuals being diagnosed later in life,¹¹ there is a growing need for improved support in the community and clinical spaces to promote self-acceptance and well-being.

For we are not difficult; we are autistic.

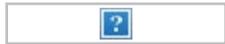
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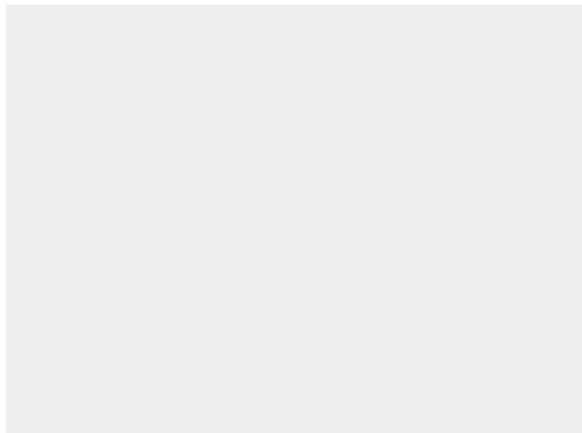
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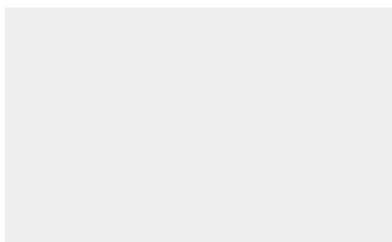
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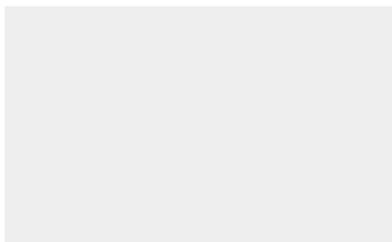
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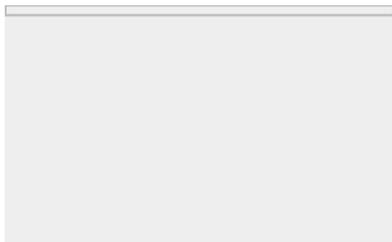
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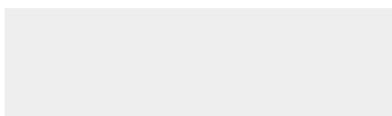
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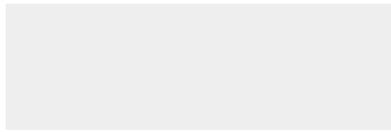


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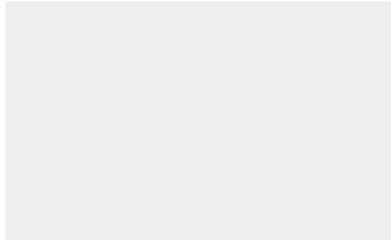


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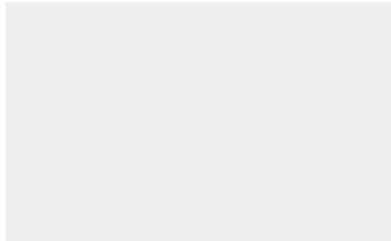




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Erin Bulluss, Ph.D., and Abby Sesterka



Erin Bulluss, Ph.D., is a registered Clinical Psychologist and consults from her private practice in South Australia. She has a passion for adapting therapeutic frameworks and techniques to suit neurodivergent clients and enjoys working with Autistic adults to develop positive Autistic identity and promote mental health. Erin also provides consultancy to psychologists and other mental health

professionals to deepen their understanding of autism and enhance their therapeutic work with Autistic adults. She completed her Ph.D. (Clinical Psychology) in the area of autism and has since published and presented internationally in this area. Erin has a social media presence, “Autistic Wellbeing Consultancy,” on Instagram and Facebook and offers online consultations through her private practice.

Abby Sesterka is an academic and research officer based in the College of Education, Psychology & Social Work at Flinders University, South Australia. Her formal background is in Indonesian languages where she has explored linguistic characteristics in minority communities. Abby has over 20 years of experience as an educator across sectors and is passionate about research focusing on inclusive education and bringing that evidence base into her own practice as an academic teacher. Abby’s research interests also incorporate linguistic and social phenomena in Autistic populations, combining her academic background with her lived experience as an Autistic woman. She has a commitment to participatory and collaborative approaches to research, teaching, and learning to support authentic narratives and empower minority voices. Abby currently serves on the board of the Autistic Self Advocacy Network of Australia and New Zealand as well as the Australian Autism

Alliance.

Erin and Abby are both late-diagnosed Autistic women who write collaboratively about issues relevant to autism, drawing from both scholarly literature and their lived experiences. Abby and Erin aim to create authentic narratives to promote acceptance, understanding, and wellbeing for Autistic individuals.

AUTHOR OF

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