

# Autism Spectrum Disorder: NETWORK NEWS

ISSUE: 54

November 2022

## AN INDIVIDUAL WITH AUTISM

OR

## AUTISTIC

### CONTENTS:

FEATURE ARTICLE  
EXCLUSIVE EVENT  
HOSTED BY THE COE ASD:  
BARRY PRIZANT  
1  
FEATURE ARTICLE  
TRY THIS  
2  
TEACHER TIP  
3  
HEAR ALL ABOUT IT  
4  
COMMUNICATION  
CORNER  
WEBSITE  
REFERENCES  
5

If you regularly read articles about autism, you may have noticed the increasing use of the term *autistic person* or *autistic individual* rather than the more familiar phrase *person* or *individual with autism*. This shift is quite noteworthy because it represents a concerted effort to acknowledge the preferences of an increasing number of individuals within the autistic community.

From the 1990's up until very recently, person-first language (PFL) was the preferred way to refer to autistic individuals. For example, we would have said *Ben has autism* rather than *Ben is autistic*. This insistence on PFL was largely a reaction to institutions/organizations who historically used identity-first language (IFL) to refer to someone on the autism spectrum and, in so doing, created the impression that ASD was both a pathological condition and the primary identity of the person. However, over the last few years, the tide has shifted largely in response to surveys that indicate that the autistic community prefers IFL<sup>1</sup>. There appear to be a variety of reasons for this preference, including:

- A strong personal identification with autism for those diagnosed, and a related viewpoint that it is not a condition that can or should necessarily change or be cured, as might be suggested or implied when PFL is employed<sup>2</sup>. More specifically, being referred to as a person with autism implies that the autism is something that could be resolved, such as when we say *a person with COVID*.

## SAVE THE DATE:

MARCH 27, 2023



Barry M. Prizant

Ph.D., CCC-SLP

[CLICK HERE!](#)

TO REGISTER

OPQ  
ACCREDITED

UNIQUELY  
HUMAN

A DIFFERENT WAY  
OF SEEING AUTISM

- A firm belief that autism is a foundational element of who they are (i.e., something intractable or permanent), particularly in the way their brains work, rather than just a small part of them or a condition they have.
- Use of IFL makes more sense intuitively and is also a simpler and more straightforward way of speaking. For example, we generally say a Scottish person or a LGBTQIA+ person, not a person with either of these identities.

Although the majority may like being referred to with IFL, the consensus within the autistic community seems to be that it is best to ask the person what they prefer. This reference to what the *autistic community* prefers introduces the seldom-discussed question of who is included in this community. The autistic individuals who are advocating either for ILF or PFL are generally those who can speak for themselves (i.e., have good verbal capacity). Thus, if we only *hear* the voices of these individuals, we may be unintentionally failing to consider the preferences of a large segment of the autistic population, namely those individuals who are less able to communicate their perspective verbally.

As educators, the Centre of Excellence for Autism (CoEASD) team is motivated to keep up with best practices and evidence-based approaches when working with students. While remaining flexible and trying to recognize each individual's preference, the current feedback from a large proportion of autistic people suggests that we should try to employ IFL in our communications as a general rule<sup>3</sup>. This is not to say that respectful discussions around this topic should cease, but simply that we will attempt to be sensitive to the evolving preferences of the community who we aim to support in our communications.

**Try This!**

Person-first language



"I am a person with autism"

Identity-first language



"I am autistic"

Neurodiversity is the idea that there are natural variations in the way people's brains work. As there are no right or wrong ways of thinking, learning, playing, communicating, or being, these differences in brain functioning should not be viewed as deficits. That said, the language we use when referring to neurodiversity matters but can sometimes be confusing. Unsure about which language to use? Rather than making assumptions, try the following:

- 1 Ask the person you are talking with
- 2 Model the language they use to describe themselves

# TEACHER TIP



Here is a great tool to help support you in making meaningful and appropriate goals for your students. The key to doing this is including the student! On the site **Autism Level UP!**, Dr. Amy Laurent and her team emphasize that this tool *“is designed to remind us that our job is to make sure that the goals included in a person’s plan center on their perspective and desires, as they are the ones who will be working towards them and, thus, it is imperative that the goals are meaningful to the person.”* Check out this link to view this checklist:

<https://cdn.sanity.io/files/p6bm7moz/production/655952605356f5964e9a83e8bbe4b97887dda51c.pdf>

<b>1. <input type="checkbox"/></b>	<b>The goal is the person’s goal and reflects their priorities.</b> Depending on the person, this information can be determined by asking them directly, by collaborating with people who know them best, or by careful observation of them and how they navigate their days.  <input type="checkbox"/> Goals ARE NOT speech’s goals, OT’s goals, etc. They are the person’s goals.
<b>2. <input type="checkbox"/></b>	<b>The goal is designed to support active engagement in environments, activities, relationships, etc. that are deemed meaningful by the person.</b> Goals may focus on scaffolding skill development in areas which facilitate engagement and participation, such as: - energy / emotional regulation - meaningful communication - cross cultural understanding - adaptive skills - motor abilities - etc. - self advocacy - organizational skills  <input type="checkbox"/> Goals are not focused on neuronormative standards. They are not aimed at “increasing or decreasing behavior” to make neurotypical people more comfortable.
<b>3. <input type="checkbox"/></b>	<b>The goal is written to include how partners will provide support and facilitate the person’s attainment of their objectives.</b> (e.g., goals might follow this template: Person will _____ when partner provides _____). Supports included are consistent with the person’s preferences and accommodate their information processing differences. Supports may include things such as: - honoring preferred communication methods - supporting unique regulatory strategies - modifying sensory properties of the environment - creating and adhering to predictable routines - giving space and time - modeling skills - offering choices - etc.  <input type="checkbox"/> Goals do not include control and compliance techniques disguised as “support” (e.g., token economies).
<b>4. <input type="checkbox"/></b>	<b>Working towards and/or attaining the goal will support the person’s self-knowledge and understanding (e.g., increase awareness of strengths and ability to advocate for necessary and rightful accommodations).</b>

## Additional Considerations:

**1. Measurability must be meaningful and not arbitrary.** “80% of opportunities” is not trackable in real life. The number of places and type of support the person accesses when using a skill to navigate their day is.

**2. During the goal writing process, teams (including the person and their family / important people in their lives) should consider if the “goal” is an opportunity for growth for the person or if it is an opportunity for partners to grow and to create more inclusive and accessible environments for the person.**



# ~~READ~~ HEAR ALL ABOUT IT:

## THE LOUDEST GIRL IN THE ROOM

Lauren Ober

As the title of her podcast makes clear, Lauren Ober loves to talk. She talks to mail carriers, dogs, grocery baggers, ticket takers, neighbours, and when alone, herself. What may seem surprising to most given her loquacious quality, is the fact that Lauren Ober is autistic. She explains that her diagnosis came from a process of “unpacking the pain and anxiety that my mouth has caused me over the years”. Remembering her early childhood, Ober cites one particularly traumatic experience wherein she was isolated behind a refrigerator-sized cardboard box to prevent her from speaking to her peers.

The Loudest Girl in the Room follows Ober’s revelation that she is autistic. Peppered through the episodes are anecdotes from Lauren’s past, amusing (yet accurate) history lessons about autism, as well as a scathing review of the cringe-worthy rom-com *Change of Habit*, where a doctor (played by none other than Elvis Presley) cures a young girl of autism through forcible hugging.

Despite the heaviness of the subject matter and the forays into some of the darker moments of the history of psychiatry, Ober manages to produce a warm and engaging narrative of her autistic journey. Anyone interested in a compelling first-person perspective of the autistic experience should *hear* Ober’s story.

The Loudest Girl in the Room is produced by Pushkin Industries, and can be found at <https://www.pushkin.fm/podcasts/loudest-girl-in-the-world>, or wherever podcasts are available.

### ASD TEAM MEMBERS

**Dr. ANDREW BENNETT**

Coordinator/Psychologist

**PATTY CLORAN**

Coordinator/Consultant for Autism

**KATIE COHENE, PhD**

Coordinator/Consultant for Autism

**SASHA DESMARAIS-ZALOB**

Consultant for Autism

**OLIVIA DI MARINO**

Occupational Therapist

**DATEVIG ETYEMEZIAN**

Consultant for Autism

**JADE LAWSANE**

Consultant for Autism

**ILANA LOGGIA**

Consultant for Autism

**HELENE PACKMAN**

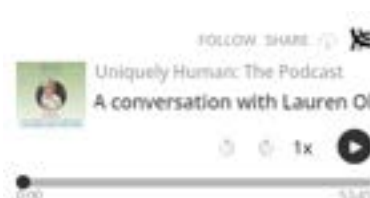
Speech & Language Pathologist

**KIM SEGAL**

Consultant for Autism

**EITHNE SHEERAN**

Consultant for Autism



# Choosing Your Words


## CAREFULLY<sup>4,5</sup>



Many teachers have adopted the use of the words “expected” and “unexpected” in the classroom to help autistic students understand how their behaviour will be perceived/received by others.

Unfortunately, in a variety of situations these well-intended professionals and/or parents end-up using these words merely as substitutes for the words “appropriate/inappropriate”. When adults use these words in this way, the purpose is usually to redirect undesirable behaviour and children typically react to them as if they were being reprimanded. Likewise, if we are telling our students “That is an expected behaviour” we are simply providing praise for an observable desired behaviour. This was never the intent of this vocabulary. The terms “expected” and “unexpected” were developed as part of the larger Social Thinking® teaching framework to help individuals with social learning challenges understand the *why* of using social behaviours in different contexts and, in doing so, improve their self-awareness and perspective-taking skills.

### Neuroclastic: The Autism Spectrum According to Autistic People

A small icon of a globe with a hand cursor pointing at it, located to the left of the section header.

This insightful website contains cost-free, ad-free content about autism written solely by autistic writers and artists. Neuroclastic Inc. is a non-profit organization whose mission is to advocate for autistic representation and human rights with the hope that this effort will, in turn, lead to a future that is more accepting and empowering for all autistic people. Rather than focusing on limitations and deficits, the articles from this website allow readers to hear and learn from the lived experiences of autistic people. Diagnosis, culture and identity, and health are just a few of the topics that are addressed. There is also an extensive section of resources which provides psychoeducation specifically geared toward the neurodivergent, parents, educators, and employers.

Please visit this website often to learn from and listen to the voices of autistic contributors.

<https://neuroclastic.com/>

## REFERENCES

- 1) <https://autisticadvocacy.org/about-asan/identity-first-language/>
- 2) <https://www.autism.org.uk/what-we-do/help-and-support/how-to-talk-about-autism>
- 3) <https://www.verywellmind.com/should-you-say-person-with-autism-or-autistic-person-5235429>
- 4) [Respecting Neurodiversity by Helping Social Learners Meet Their Personal Goals](#)
- 5) [Teaching Expected & Unexpected Behaviors the Right Way](#)