

Autism Demystification

Review Padlet

<https://padlet.com/nicolettvargass/autismdemystification>

Anna Bowerman, Courtney Holton,
Meagan Rose Baron, Nicolett Vargas, Suttera Samonte

SPED 794 Socialization and Imagination: Autism (Spring 2021)

To begin...

We want to disclose that the purpose of this project is not to defer from the voices of autistic individuals but use our role as allies to raise them.

As professionals seeking/specializing to work with autistic children/persons in the field of education and speech therapy, there is a certain privilege in knowledge we have on autism. We hope to share these resources created by organizations run by autistic self-advocates to help fight the oppressive forces that prevent progression towards a more inclusive society.

What is an ally?

“An ally is a person with privilege on a particular axis who makes a conscious choice to work against oppression on that axis. In this instance it’s a non autistic person working with and for autistic rights...” (Kassiane, S., 2012) - via Autistic Self Advocacy Network

Questions we posed:

- What do general populations know about autism?
- What are the common misconceptions that need to be demystified?
- What can we do to bridge the gaps in knowledge as allies and amplify autistic voices?

Our Plan

To understand what a “general population” understands/knows about autism, we took to a common platform that is open to everyone--SOCIAL MEDIA! (Specifically, Instagram!) Upon distribution of a pre-survey, we created a collection of resources on autism and shared it with our followers, followed by a post-survey. We invited autistic and non-autistic participants to respond.

We used the following protocol:

- Pre-Survey
- Sharing of resources based on the knowledge/questions of participants
 - i.e., Padlet
- Post-Survey

Common Themes

Upon review of the different thoughts and questions posed by the participants, we used that information to gather resources relevant to the gaps in knowledge.

From our research, the following were common themes:

- Terminology
 - The Spectrum
 - Autistic or Autism?
- Understanding challenging behaviors
- Alternatives to Applied Behavior Analysis (ABA)

Pre Survey Questions

1. What is the first word that comes to mind when you hear, "autism" or "autistic"?
2. How much do you feel you know about autism?
3. Do you know anyone with autism?
4. How did you learn about autism?
 - a. (Ex: Media, TV, Relative, You're Autistic, etc.)



Pre Survey Questions (Cont.)

5. Are you an educator, therapist, parent, or both?

(i.e. educator, parent or therapist)

6. What's a question you may have about autism?

7. If you are autistic or know someone who is autistic, what would you like people to know?



How much do you feel
you know about
Autism?



Average answer



21 people answered. This is the average answer.



27 people voted. This is the average answer.

Do you know anyone who is
Autistic?

YES

NO/NOT
SURE

Do you know anyone with
Autism?

YES ✓
84%

NO/NOT
SURE
16%

Do you know anyone who is
Autistic?

YES
88%

NO/NOT
SURE
12%

A Yes

20

✓ No

1

C I don't know

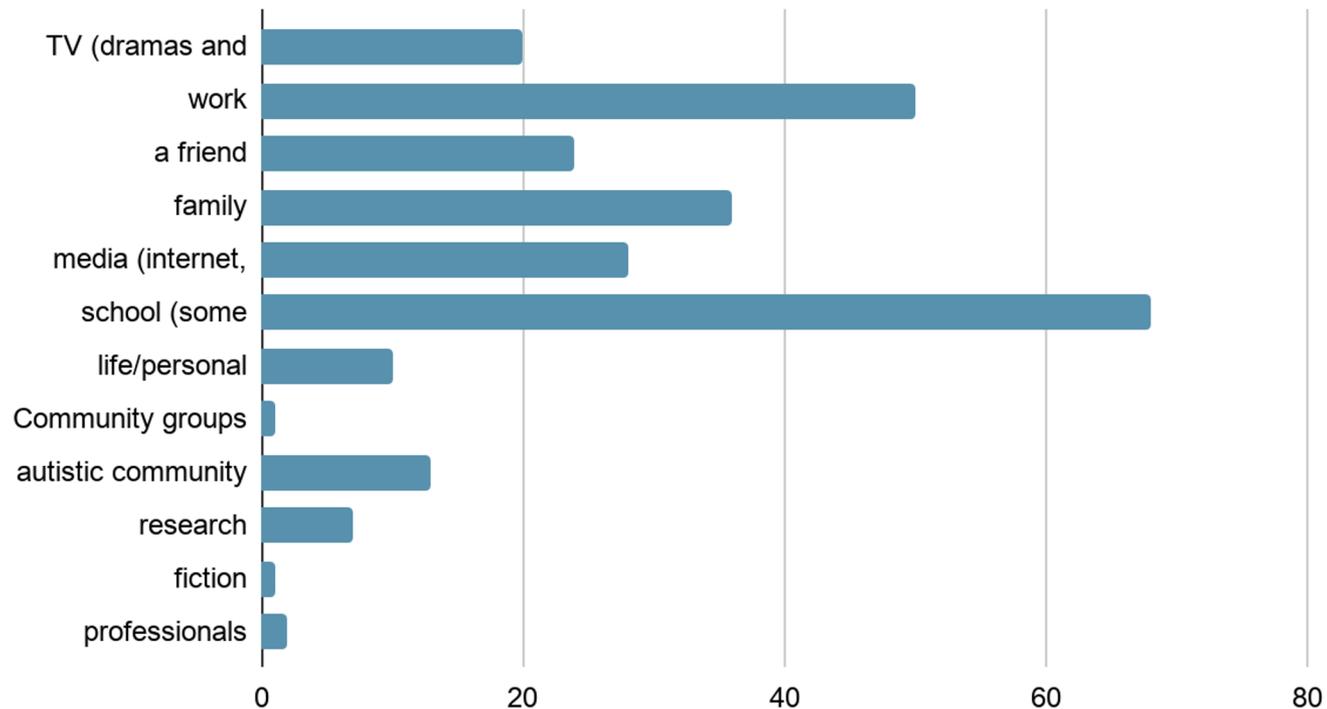
2

How have you learned about Autism?

Type something....

(ex: media, school, tv, relative, you're autistic, etc.)

How have you learned about autism?



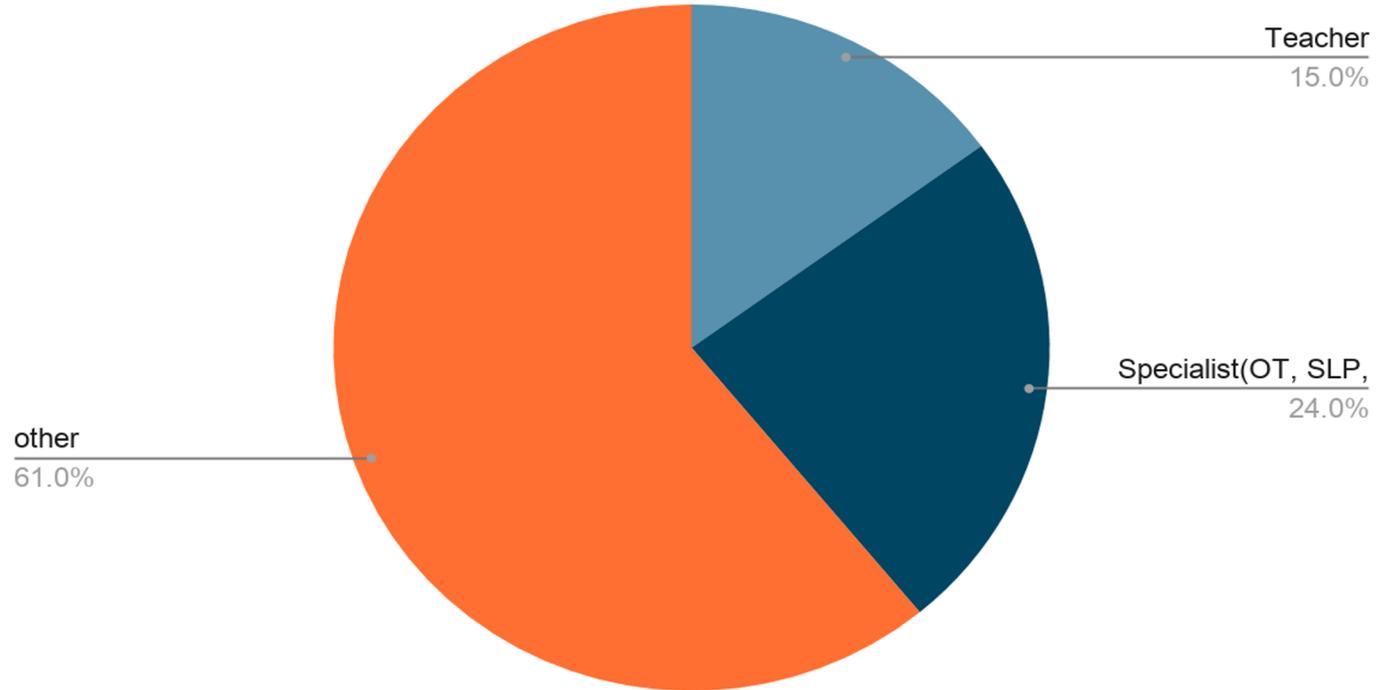
ARE YOU AN EDUCATOR AND/OR THERAPIST?

(A) teacher

(B) specialist (OT, SLP, PT, psych, etc.)

(C) neither

Are you an Educator or Therapist?



"How can I continue to share what autism is without stepping over my my boundaries as non-AS"

"Is there such thing as 'the spectrum' or is that just culturally made up"

"How to act around/treat someone with Autism"

"How to better support families with Autistic family members or children"

"Many coworkers are autistic, how to respect and work alongside those with Autism"

"How to better support students with autism"

"Does he love me like I love him"

What's a question that you may have about Autism?

"How to shape echolalia into more functional language"

"The science behind how/why a baby is born Autistic"

"What is the best way to describe autism to a child"

"What's the best way to be supportive of someone who is Autistic"

"'Person with Autism' or 'Autistic person?'"

"How to better understand it so I'm not intimidated by it"

"How can society become more accommodating for people with Autism"

"Is ABA therapy actually helpful/good"

"Personally, what are the best techniques you've used when working with them"

"Early signs? When can it be diagnosed"

"Can you find out while pregnant if your child is going to be autistic"

"How to remove stigma that people with Autism are slow. They are genius"

"Everyone is different! Embrace and celebrate differences. Pass on and teach inclusivity"

"I say and do many things not knowing that it's "inappropriate". Please be nice & accepting"

"If you meet a kid with autism, you have met one kid with autism. They are unique and are all smart and amazing in their own ways"

"Be patient, mindful, and provide alternatives for success for everyone"

"They have so much to offer this world. They are beautiful in so many ways. Lights in the dark"

If you are Autistic or closely know someone that is Autistic



what is something (or many things) you want people to know?

Type something....

"I'd rather people be honest than go behind my back and say that I'm weird. I'm not trying to be weird, I just need help with social cues"

"I wish that people can just be like oh, everyone is quirky!"

What have you done so far?

You've shared
some of what you
THINK / KNOW
about autism.



You've asked
QUESTIONS
that you want
to learn about



While you watch the videos on the next slide try to think about...

What does autism look like in children and adults?

Why do people with autism stim? (refer to terminology slide for definition of stim)

Do people with autism have a difficult time making friends?

How do I treat someone with autism?

How do people with autism want to be treated?





Terminology

Defined by an Autistic
influencer on Instagram:
[@_ninstagram_](#)

Autistic or Autism?

Ask the autistic person what they prefer!

Individualized preference based on the autistic person.

When writing about autism, you have a choice to say “autistic person” or “person with autism”, just keep it consistent throughout your work.

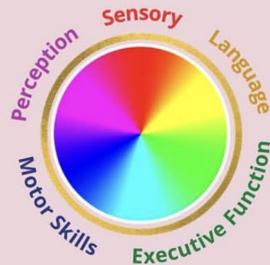
“THE SPECTRUM”

AUTISM IS A NON-LINEAR SPECTRUM

It does **not** look like this:



Autism is much more **complex** and **dynamic**. Every autistic individual is **unique**, and so are our traits and support needs. We all have varying degrees of autistic traits. Some may have serious sensory issues, while others have none, and so on. There is **endless variation**, and they change and evolve throughout our lives, even from day to day.



It looks more like this



@_ninstagram_

DON'T USE 

DO USE 

High functioning /
low functioning 

Autism / autistic

Non-verbal 

Nonspeaking

Severe, moderate,
mild... 

Autism / autistic

Illness, disease... 

Disability, condition

Suffer from 

Is autistic / has autism

@__ninstagram__

"SPECTRUM" SCALE LANGUAGE

Instead of >

High Functioning > **Low Support Needs**

Moderate Functioning > **Moderate Support Needs**

~~Low Functioning~~ > **High Support Needs**

**Below is a resource to explain in more detail on spectrum functioning terminology:

<https://www.learningdisabilitytoday.co.uk/why-highlow-functioning-labels-are-hurtful-to-autistic-people>

Why Functioning Labels Harm All of Us

High Functioning

"High functioning" invalidates our struggles and support needs. It is a measure of our 'masking' abilities, and we are held to unreasonable neurotypical standards, which often leads to autistic burnout. It can be very difficult getting the support we need since we are often told we are just using our autism as an excuse and to stop being dramatic when we talk about our struggles.

Low Functioning

"Low Functioning" invalidates their strengths and talents, and they are often dismissed and stripped of their autonomy. It implies that they are defective because society sees them as a burden. They are often denied opportunities and exposed to abusive therapies to make them more "normal".

@_instagram_



neurodivergent

[noor-oh-di-vur-juhnt]

neurodiversity refers to variation in the human brain. The term emerged as a challenge to prevailing views that neurodevelopment disorders are inherently pathological, and instead follows a social model of disability, in which societal barriers are the main contributing factor that disables people.

@_ninstagram_

neurotypical

[noor-oh-tip-i-kuhl]

neurotypical or NT—short for neurologically typical—is widely used by the autistic community to refer to non-autistic people. More generally, neurotypicals are people who do not have a neurodevelopment or learning disorder.

@_ninstagram_



stimming

[stim-ming]

self-stimulatory behavior, stims, or stimming, can help autistic people cope with sensory overload, anxiety, and overwhelming emotions (also positive). It can be repetitive motions such as hand flapping, repetition of words or noises, rocking, leg bouncing, and rearranging objects. Most stimming is completely harmless, and it is not exclusive to children or autistic people. Most people stim, and it should not be discouraged unless it is very disruptive.

@_ninstagram_

echolalia

[ek-oh-ley-lee-uh]

people with echolalia repeat noises and phrases that they hear. It may include questions, quotes from favorite movies, or verbal commands. It can be a form of self-stimulatory behavior or a way to communicate ideas when it is difficult to formulate new or spontaneous speech. It can both be immediate or delayed. It has communicative intent.

@_ninstagram_

meltdown

[melt-doun]

a meltdown is an intense response that occurs when the systems become overwhelmed with sensory input and/or other stressors. It might include inability to speak, lashing out, crying, screaming, or running away. It is NOT a temper tantrum, nor is it voluntary.

@_ninstagram_



masking

[mas-king]

due to the stigma surrounding autism, many autistic people learn how to mask autistic behavior. Masking behavior includes controlling impulses (such as stimming), mimicking socially accepted behavior—such as maintaining eye contact—and rehearsing answers to questions. Masking can often help autistic people "fit in" better; however, it often comes at a high cost, including extreme exhaustion and anxiety. Masking is especially prevalent among women who risk late or missed diagnosis. Many aren't aware that they are masking, and some mask so much that they no longer know who they are without it. Autistic people shouldn't have to mask who they are.

@_ninstagram_

Understanding Challenging Behaviors

"Here is the important irony: Most of the behaviors commonly labeled 'autistic behaviors' aren't actually deficits at all. They're strategies the person uses to feel better regulated emotionally. In other words, in many cases they're strengths." - Prizant & Fields-Meyer

Challenging Behaviors = **COMMUNICATION**

Self-Regulation: Most people with autism develop coping mechanisms to help self-regulate. A neurotypical peer/adult may see these behaviors as challenging or unacceptable because it's not the same way they cope.

Accept and foster differences rather than trying to change them or "cure" them.

You may be able to relate in understanding that shaking your leg or tapping your pen on the table helps to regulate and calm you.



It is not a neurotypical person's place to say whether the way an autistic person copes is acceptable or not. The autistic person need not change their ways of self-regulating so others can feel more comfortable. We know they are integral to meet physiological needs; to not feel overloaded with information and/or disconnected. **With this knowledge, we can shift the way these behaviors are viewed.**



Understanding Challenging Behaviors

Some examples mainstream society has deemed “unacceptable” or “challenging” behaviors include:

- Stimming (see stimming slide)
- Gross/fine motor movement - jumping, running, pushing, squeezing, tapping, wiggling, hanging upside down
- Humming or singing

Instead of “unacceptable” or “challenging behaviors” we can say “coping mechanisms” or “responses to overstimulation”

- These behaviors serve the function of communication
- We are all unique in the way we communicate. We all communicate with both language and/or our bodies (whether we are neurodivergent or not)

The ONLY behaviors we should try to minimize are behaviors that are harmful to themselves or their peers. *See notes below for more.

Understanding Challenging Behaviors

Resources we have found helpful:

Instagram Accounts:

@raisinghumankind

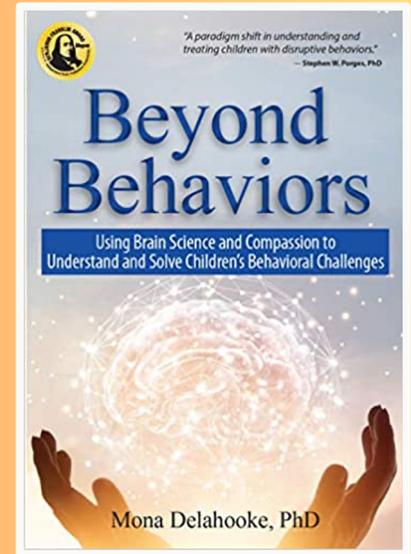
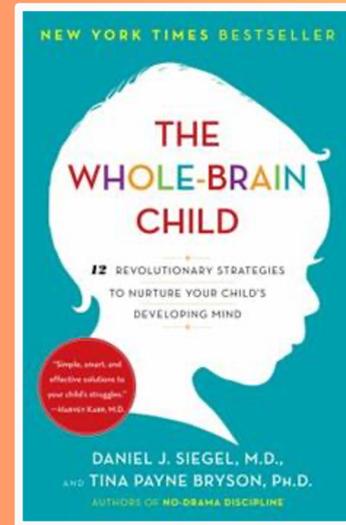
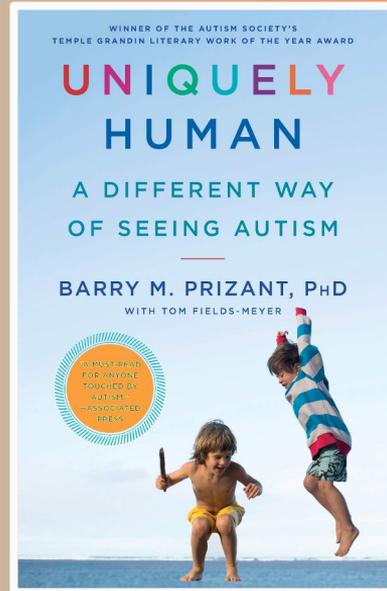
@the.autisticats

@theautisticlife

@neurodivergentactivist

@nigh.functioning.autism

@fidgets.and.fries



Some Alternatives to ABA

DIR/Floortime

- ★ The Developmental, Individual Difference, Relationship-based Model
- ★ Form a sense of self to develop language and social capacities
- ★ Progress through functional emotional developmental capacities.

SuperFlex - Teaching Social Thinking

- ★ Teaches social concepts and understandings of social interactions
- ★ Develops social competences
- ★ <https://www.socialthinking.com/Products/superflex-superhero-social-thinking-curriculum>

Integrated Playgroups (IPG)

- ★ Guides autistic children and neurotypical peers in mutually engaging experiences
- ★ Fosters socialization, play and imagination in natural inclusive settings
- ★ Engaging in age appropriate and culturally valued activities
- ★ <http://www.wolfberg.com/>

Brief (5 minutes)...

Post-Survey Questions & Feedback

Post Survey Questions

*Please respond to these questions in the notes below the slide.

1. How much do you feel you know about autism now that you've looked through our resources?
2. What's one (or more!) new thing that you learned about autism?
3. Were there any changes to what you thought about autism? (Pre/Post-Survey)
4. After swiping through our resources, do you have any questions?

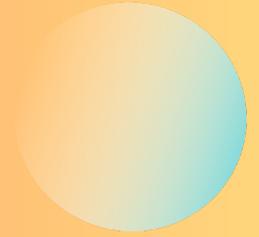
Please share your feedback
on the next 3 slides: (1-2 minutes to do:)

How important was
this information to
you?

How satisfied are
you with the way it
was shared or
explained?

1. Videos from Autistic People
2. Terminology
3. Behavior (challenges and alternatives to ABA)

POST-SURVEY ANSWERS



1. Videos from Autistic People

Drag circle
to your
response:)

Important	Just a little	Not Important
I want to learn this I need this information	Some of it No big deal	I don't care about it Doesn't matter to me

Drag circle
to your
response:)

Satisfied	Sort of	Not Satisfied
They were awesome They were helpful They addressed my questions	In some ways Not all the time	I wish it was different Things need to change It's not going well

1. Videos from Autistic People

Drag circle
to your
response:)

Important	Just a little	Not Important
I want to learn this I need this information	Some of it No big deal	I don't care about it Doesn't matter to me

Drag circle
to your
response:)

Satisfied	Sort of	Not Satisfied
They were awesome They were helpful They addressed my questions	In some ways Not all the time	I wish it was different Things need to change It's not going well

1. Videos from Autistic People

Drag circle
to your
response:)

Important	Just a little	Not Important
I want to learn this I need this information	Some of it No big deal	I don't care about it Doesn't matter to me

Drag circle
to your
response:)

Satisfied	Sort of	Not Satisfied
They were awesome They were helpful They addressed my questions	In some ways Not all the time	I wish it was different Things need to change It's not going well

2. Terminology Explained

Drag circle
to your
response:)

Important	Just a little	Not Important
I want to learn this I need this information	Some of the it was useful These weren't a big deal	I didn't care about these terms Doesn't matter to me

Drag circle
to your
response:)

Satisfied	Sort of	Not Satisfied
It made sense These terms feel clear	Some of it was clear Some was unclear	I wish it was different I wish it was explained another way

2. Terminology Explained

Drag circle
to your
response:)

Important	Just a little	Not Important
I want to learn this I need this information	Some of it was useful These weren't a big deal	I didn't care about these terms Doesn't matter to me

Drag circle
to your
response:)

Satisfied	Sort of	Not Satisfied
It made sense These terms feel clear	Some of it was clear Some was unclear	I wish it was different I wish it was explained another way

2. Terminology Explained

Drag circle
to your
response:)

Important	Just a little	Not Important
I want to learn this I need this information	Some of it was useful These weren't a big deal	I didn't care about these terms Doesn't matter to me

Drag circle
to your
response:)

Satisfied	Sort of	Not Satisfied
It made sense These terms feel clear	Some of it was clear Some was unclear	I wish it was different I wish it was explained another way

3. Behavior Slides (challenges & alternatives to ABA)

Drag circle to your response:)

Important	Just a little	Not Important
I wanted to learn this I needed this information	Some of the time No big deal	I don't care about it Doesn't matter to me

Drag circle to your response:)

Satisfied	Sort of	Not Satisfied
It was awesome It was clear It was useful	Some of it made sense Some ideas were unclear	I wish it was different It didn't address my question(s)

3. Behavior Slides (challenges & alternatives to ABA)

Drag circle to your response:)

Important	Just a little	Not Important
I wanted to learn this I needed this information	Some of the time No big deal	I don't care about it Doesn't matter to me

Drag circle to your response:)

Satisfied	Sort of	Not Satisfied
It was awesome It was clear It was useful	Some of it made sense Some ideas were unclear	I wish it was different It didn't address my question(s)

3. Behavior Slides (challenges & alternatives to ABA)

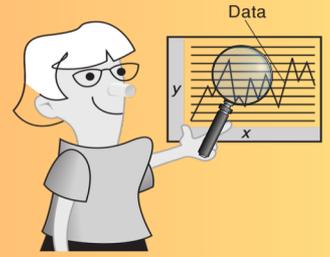
Drag circle to your response:)

Important	Just a little	Not Important
I wanted to learn this I needed this information	Some of the time No big deal	I don't care about it Doesn't matter to me

Drag circle to your response:)

Satisfied	Sort of	Not Satisfied
It was awesome It was clear It was useful	Some of it made sense Some ideas were unclear	I wish it was different It didn't address my question(s)

Reflection - Nicolett Vargas



This project helped me understand what my friends and family know about autism. To my surprise, many people feel they know quite a bit of information about autism. This was interesting to me because as a student who is specializing in autism, I feel I know very little about the condition. Our group had a great idea, by posting the pre survey to social media. It is a widely used platform and I received more responses and interest than I thought I would. Many of my friends and family wanted to know more about autism, specifically how to make people and students with autism feel comfortable. After collecting pre interview questions, our group was able to decide the most common questions and interests our participants shared. From there, we collected and shared resources made by individuals with autism. We wanted to ensure that our participants had information that was relevant, but also kept in mind how overwhelming articles and wordy slides can be. Many participants commented on the use of visuals, simple slides and the links to resources they could use if they wanted more information. Most of the people who participated in this activity were educators and they positively responded to the information.

Due to a lack of time to send out information (the presentation and the padlet) and collect data for the post survey, I only received three post survey comments. However, I feel the information we collected and stigmas we demystified are helpful for many of my instagram followers to know. I will continue to post this presentation and the padlet we created to all my social media platforms as well as at my school site. I feel this information is helpful for general education and special education teachers, as well as parents and students to know about.

Reflection - Courtney Holton

The process of both seeking information and advocating for the autistic community has been really eye opening for me. I learned a lot of my close friends and family know someone who is autistic, or even related. Sharing the updated terminology and emphasizing the importance of listening to the autistic voices is extremely powerful, especially sharing it through a social media platform. The more advocacy I post on my instagram stories, the more people will read about these things and become more informed and curious to know more. When more of the general public understand and practice these terms, the more people will follow suit.

In order to receive feedback on our padlet and our powerpoint presentation, we chose to send it out to a select few who we know participated in the pre-survey. That way we could reflect and inform ourselves on how we could improve our execution. I learned from my two post-participants that they learned more than they had expected. One learned about masking and I think that's one of the most underexposed term in the autistic community. Masking is a huge issue and can traumatize an individual and can be harmful for one's mental health, especially in women.

I think if we had more time I would research more commonly mistaken terminology and write up some sort of glossary. I would also share this presentation to the parents at my school, alongside colleagues so we can get direct feedback from parent voices themselves. Parent voices are just as important to make the flow of support work. Our questions would have been more specific to educators and/or parents, so we would have been able to gather more concrete knowledge of the direct community. This project has helped me understand what I need to do to advocate for the neurodiverse community and to continue my work keeping the general population exposed to differences, inclusion and acceptance.



Reflection - Suttera Samonte

With the past month being Autism Acceptance month, it seemed like the timing of this project was just right. However, being reminded of the purpose of this project (i.e., autism demystification and autism advocacy) and being a listener to the autistic community, I am also reminded that this is not enough. I really appreciated my followers' vulnerability and willingness to share. It was very interesting to see the responses/questions received about autism during the initial intake, and it's just a reminder that there is a while to go. As allies, we must go beyond spreading awareness and push for acceptance of neurodiversity. It goes beyond spreading information but actively making moves against anything that is anti-autistic.

As a future SLP hoping to work with autistic clients, I think of what I can do. There are so many biases against autistic persons and their livelihood within the current scopes of therapy, I think about how I can advocate for inclusivity along with complimenting communicative abilities. I hope to continue to learn and humble myself in my position as an ally. I am not speaking for, but amplifying autistic voices.

Within the scope of this project and due to time constraints, I wasn't able to collect as much data as I did from the initial survey (about 50 participants pre-survey) in comparison to the post-survey (5 participants post-survey). If I were to re-do this project, I would definitely distribute all information more ahead of time in order to give followers more time to digest and make less-time restrained reviews. I also would have loved to collaborate with individuals who identify with the autistic community and ask about their thoughts and what would actually be helpful in terms of autism demystification. Through this collaboration, allies and neurodiverse people alike can work towards a common ground. Even if we are listening, non-autistic persons/allies will never truly know what being autistic means. We need to reflect on ourselves, our environments, etc., and ask what we can do to be better.

Reflection - Anna Bowerman

This project, beginning to end, was an extremely enlightening experience for me. I gained insight to help guide my practice with future clients and advocacy work in the future. Through courses I've taken throughout my graduate career, I realize that although I still place high importance on helping my clients advocate for themselves; it is also the community at large that is responsible for doing our part in understanding and advocating for those that are misrepresented. It was a great experience to compile information and share what we have all found, and it will be forever useful to have resources from this presentation and our Padlet to share with other professionals, members of the community, and parents alike.

One of the most enlightening parts of this project was reaching out to my friends, family, and acquaintances on social media to take part in the pre-survey questions. The answers I got were both endearing and surprising. It was wonderful how many people knew so much about autism, were autistic, or had family members who were autistic that were eager to speak forth as an ally. On the other hand, it should be of not much surprise but it was eye-opening to see how far we must come to bring awareness to what the experiences of autistic people comprise of. Although many people gave descriptions that were surprising to me, those same people had such significant questions they were comfortable asking that helped so much to guide our project. Because of the time constraint, we did not get as much feedback as we would have liked. I would love to get the perspective of autistic friends and how they felt it represented themselves and their community.

Reflection - Meagan Rose Baron

I found the process of organizing a program for autism demystification valuable and relevant. We started our project by brainstorming how to reach our audience, and what they might need. We decided to apply similar practices as I might in a classroom: know, want to know, learned. We polled our audience about what they KNOW, then encouraged them to ask a question. Then based on their knowledge and their curiosity we curated resources and addressed specific topics.

Before even reviewing the input we received, I deeply appreciated the scaffolding of this process. On my own, as an SLP in the working world, setting up a program or professional development like this would feel like a monumental task. I see now that it does not have to be. We are here as allies to amplify autistic voices. Our project shared information, but did not counsel by persuasion. Instead, we listened first to our audience, then shared relevant information created by autistic people. Based on the feedback we received in our post-survey, those who consumed our presentation found the information “just a little [important]” to “Important” and were “Sort-of [satisfied]” to “Satisfied”. Our audience rated the videos from autistic people were particularly important and satisfying. I appreciated that our audience came to their own conclusions about the value of listening to autistic voices. I feel in this respect we effectively and respectfully shared information, in a context that allowed our audience to be receptive. Our audience rated the terminology slightly less important and sometimes unsatisfyingly explained. Next time I facilitate an autism demystification program, I might try pre-viewing specific vocabulary and see what people think they know, then comparing their own responses to see if anything changes.

Overall, I found this project eye-opening. I appreciated people’s willingness to share, but I also learned so much myself by delving into resources to share based on the needs at hand. I was reminded of the pleasure and impact of simply staying curious on the learning process.

Thank you for
your time!

