Division of Rheumatology, Allergy & Immunology





### • DEI Activity: Understanding Neurodiversity

## **DEI Activity: Understanding Neurodiversity**

# **Understanding Neurodiversity**

TARC/ RAI All Staff and Faculty Meeting Friday, May 24, 2024

## Acknowledgments – TARC / DRAI DEI Workgroup and DEI Day Facilitators!!

Patricia Owens Abby Mihalkovic Astia Allenzara Brian Diekman Sam Stuppy **Garrett Sessions Jacqueline Shine** Will Frickhoeffer Elena Filippova Xinyi (Melissa) Li

Becki Cleveland Amanda Nelson Leigh Callahan **Beth Jonas Richard Loeser** Liubov Arbeeva **Kirsten Ambrose** Millie Kwan Lara Longobardi Tessa Englund Abby Gilbert Prarthana Jain

Rumey Ishizawar Tessa Walker Mary Hale

## Word Cloud Activity : What does neurodiversity mean to you?



When poll is active respond at **PollEv.com/onyinyeiweal958** Send **onyinyeiweal958** and your message to **22333** 

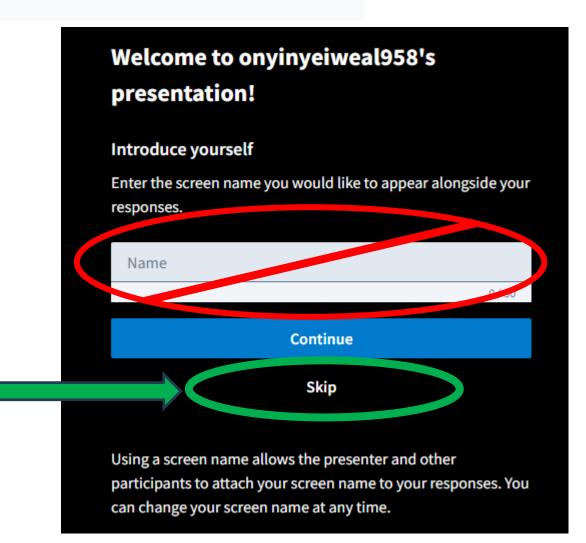


## Word Cloud – polleverywhere.com

You can submit multiple answers

## **Participation is voluntary**

All submissions are anonymous



## Word Cloud Activity : What does neurodiversity mean to you?

Join by Web

### PollEv.com/onyinyeiweal958

Join by Text

Send onyinyeiweal958 and your message to 22333

Join by QR code Scan with your camera app



All submissions are anonymous

# **Today's Objectives**

- To define neurodiversity (vs. neurotypical)

 To introduce the concept of the Social Model of Disability and application to neurodiversity

- To highlight experiences or emotions that we may all share, whether we identify as neurotypical or neurodiverse

## **Rules of Engagement**

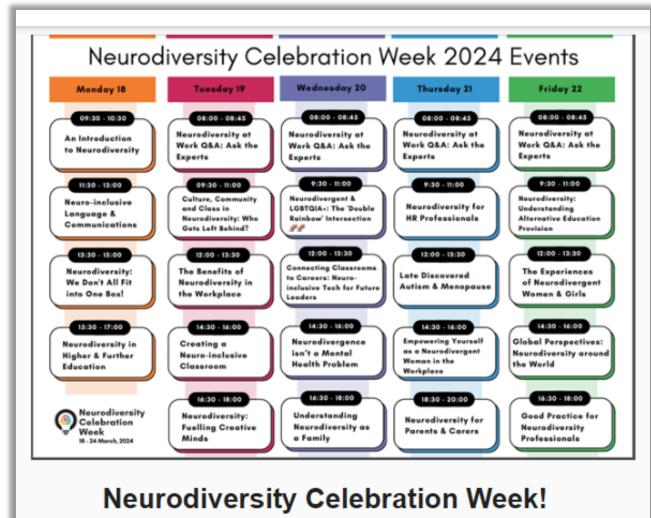
SCHOOL OF

- Participating in this activity is strictly voluntary
- Respectfully listen to and dialogue about your perspectives and those of others and ASSUME BEST INTENTIONS!
- Aim to respond rather than react
- This is meant to be a Safe Space to dialogue about challenging topics; do not assume that it is also a comfortable space
- Be open-minded and willing to embrace new ideas and strategies
- Please **participate as much as you are comfortable and able**. Your questions and comments enrich what you and others gain from this activity.

Office of INCLUSIVE EXCELLENCE

# Why the focus on neurodiversity?

### Neurodiversity is in the media, pop culture, and our social consciousness

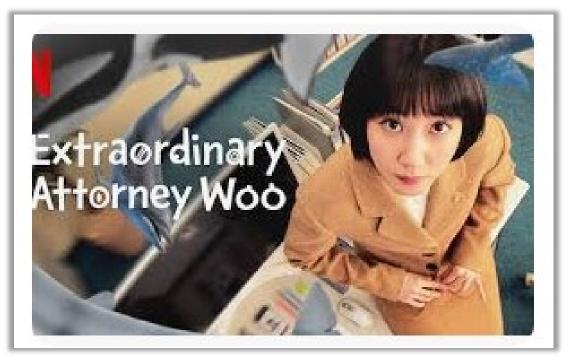


# Why the focus on neurodiversity?

## Neurodiversity is in the media, pop culture, and our social consciousness



"By sharing his story and embracing his autism, Keir Gilchrist has become an inspiration for others who may be navigating similar paths...[and] helped foster greater awareness and acceptance of autism in society"



South Korean TV series starring Park Eun-bin as "Extraordinary Attorney Woo," a rookie attorney with autism working in a major law firm in Seoul

## **Amusement parks and neurodiversity**

### Morgan's Wonderland–San Antonio, TX



### **Amusement parks**

more. For kids on the autism spectrum, there's an entire <u>Sensory Village</u>: it's free of bright lights and loud noises. There are tons of imagination stations, a Saddle-Up Stable with an (electronic) horse ride, places to paint, make movies and build, a Village Market

#### Morgan's Wonderland

If you haven't heard about Morgan's Wonderland, it's the world's first amusement park that was built specifically to be all-inclusive for children (and adults) of all abilities and ages. Named after the founder's own daughter, who has severe cognitive delays and physical disabilities, Maggie and Gordon Hartman wanted a place where families could be together on vacation, no matter their abilities. The park features <u>a carousel</u> that

# **Neurodiversity on Broadway**

### **Broadway Musicals**



### **Stories of Adults with Autism**

A new play was performed in theaters that highlights the stories of adults with autism. Some of the performers are on the autism spectrum. There are also spaces in the theatre for people who might get overstimulated during the show.

# **Neurodiversity in biomedical sciences**

## ASBNBTODAY THE MEMBER MAGAZINE OF THE AMERICAN SOCIETY FOR BIOCHEMISTRY AND MOLECULAR BIOLOGY

y youngest daughter has always been special, with a fantastic way of thinking and acting that society told us was "outside of the norm." When she started to struggle at school, her therapist suggested that she may be autistic. As I read up on the topic, I started to wonder if perhaps I was as well; I received my autism diagnosis one year after she got hers. I was 41 years old at the time and a postdoc at the University of Michigan.

At first, I didn't quite know what to do with this information. Growing up poor in 1980s Germany, I had always been the "socially awkward" kid nobody really understood but many took advantage of. I had trouble connecting with my peers, often being told that I was too blunt. As an adult, I had carried the feeling that something was seriously wrong with me, which made other people simply not like me.

### Impacts on science, scientists, and the scientific community

Simone Brixius–Anderko



# UNC-Chapel Hill and Neurodiversity

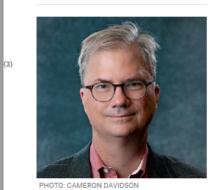
- Holden Thorp in the *Science* (April 25, 2024)
- Editor-in-Chief at *Science* Family of Journals
- Served as UNC-Chapel Hill's 10<sup>th</sup> Chancellor from 2008 to 2013

### Science needs neurodiversity

#### H. HOLDEN THORP Authors Info & Affiliations

SCIENCE • 25 Apr 2024 • Vol 384, Issue 6694 • p. 365 • DOI: 10.1126/science.adq0060

15,963



All brains work differently. Individuals process information and engage with the world in ways that are influenced by a multitude of biological, cultural, and social factors. In the world of science, these differences are what spark innovation. This is why the scientific community needs to better recognize the enormous potential of neurodiversity and bear in mind that certain behavioral and cognitive traits that may strike some as unusual can be catalytic to the scientific quest.

"hard to read" "wooden" "monotone" Challenges navigating social situations Differences in eye contact, hand motions, tone of voice

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# UNC-Chapel Hill and Neurodiversity

"Some neurodivergent people are meticulously observant and are able to connect seemingly disparate concepts—assets in the world of science. This should make science a comfortable place to call home, yet not everyone feels so included. This must improve."

### Science needs neurodiversity

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SCIENCE • 25 Apr 2024 • Vol 384, Issue 6694 • p. 365 • DOI: 10.1126/science.adq0060



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PHOTO: CAMERON DAVIDSON

"reduce the stigma and exclusion"

## Why the focus on neurodiversity?

# It impacts our patients, our study volunteers, our families, colleagues, and ourselves

Why focus on neurodiversity? Perspectives from TARC / RAI?

- Brian Diekman
- Mary Hale



### How to ADHD •

@HowtoADHD · 1.7M subscribers · 377 videos

Have ADHD? Know someone with ADHD? Want to learn more? You're in the right place!

howtoadhd.com and 4 more links



# neurodiversity

(n)

the concept that there is natural variation in the human brain that leads to differences in how we think and behave.



Differing Minds

Workplaces Education About Contact Log In

# Making everyone, and everywhere, neuroinclusive!

https://www.differingminds.co.uk/



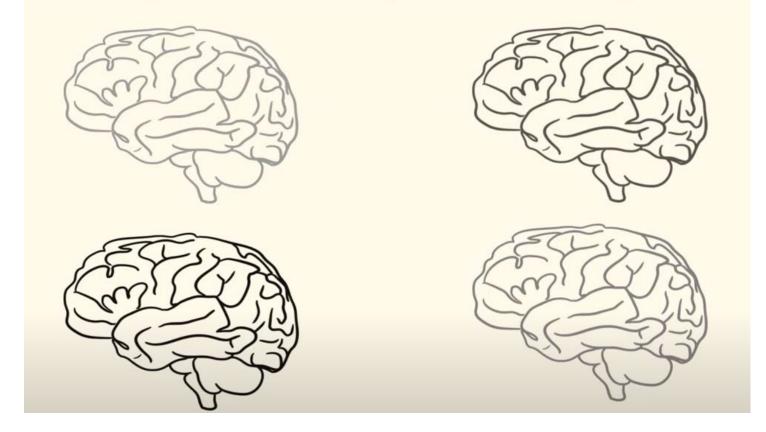
UNIVERSITY OF NORTH CAROLIN





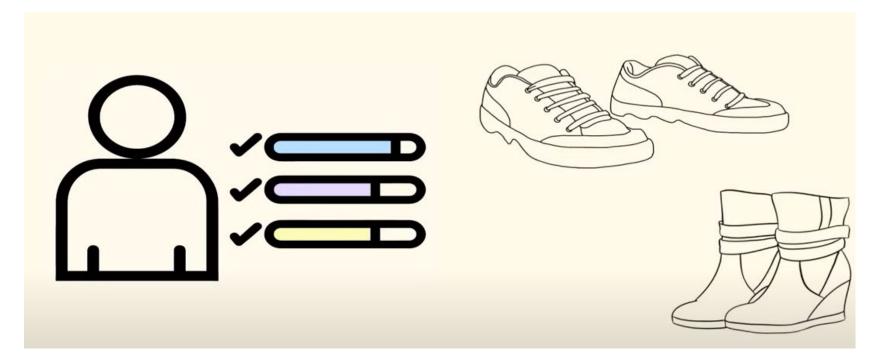


"But for the majority of people, their brains are similar enough that there are no obvious differences in how they function."





"They have differences in things like skills, preferences, and styles. But mostly their brains perceive the world in [more or less] the same way"



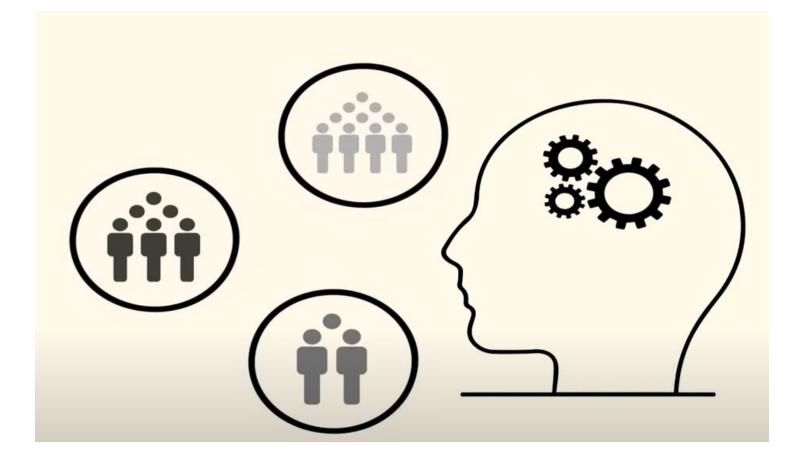


"But for others, their brains are more fundamentally different."



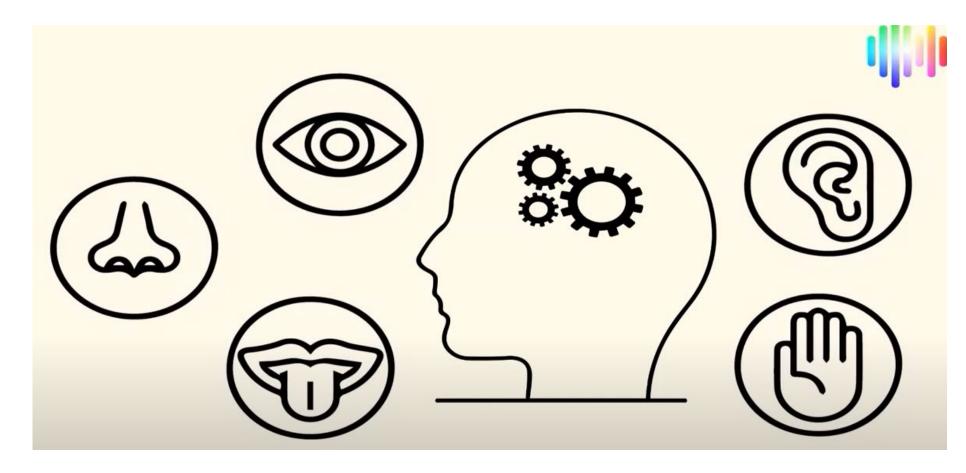


"They have differences in things like social understanding..."



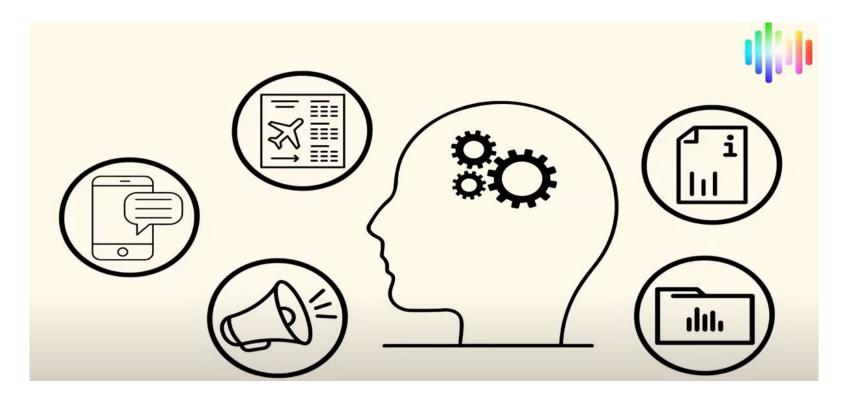


"...and sensory processing..."





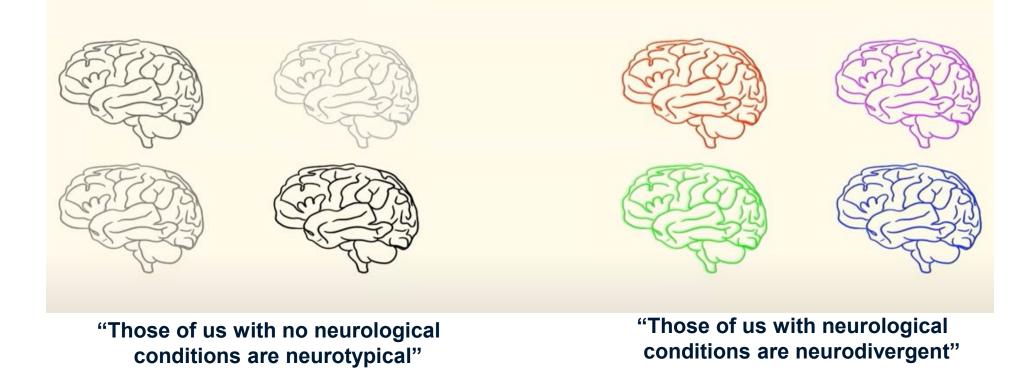
"...communication, and information processing..."





"This natural variation in our brains is called neurodiversity."

# Neurodiversity





**Diagnoses or conditions classically considered neurodiverse:** 

# autism ADHD dyslexia dyspraxia dyscalculia tourette's syndrome dysgraphia

**ADHD = Attention Deficit Hyperactivity Disorder** 

# **Common in the United States**

## **Conditions considered neurodiverse include:**

### • Autism = Affects 1 in 36 children in the US

 Autism Spectrum Disorder – Differences in the brain that can impact social communication and interaction or promote restricted or repetitive behaviors or interests. People with ASD may have different ways of learning, moving or paying attention



Greta Thunberg, Climate Activist



Daryl Hannah, Actor



Sue Ann Pien, #ActuallyAustistic Actor



Steve Jobs, Former Apple CEO

ADHD = ~11.3% of kids between 5-17 (~6.1 million) and 4% of adults (~8.7 million)

- Attention Deficit Hyperactivity Disorder
  - Symptoms can include:
  - Remaining focused in a task, especially for long periods
  - Organizing activities
  - Prioritizing tasks
  - Following through and completing tasks
  - Forgetfulness
  - Time management (e.g., missing appointments or deadlines)



Trevor Noah, Former Host of the Daily Show

Simone Biles, World Class Gymnast



Penn Holderness, The HoldernessFamily.Com



David Kwan, Director, "Everything, Everywhere, All at Once"

## **Conditions considered neurodiverse include:**

- Dyslexia = Affects 5-10% of the population, but may be as high as 17%
  - Learning disorder that involves difficulty reading due to problems identifying speech sounds and their relationships to letters and words



### Cher

Legendary singer and actor who struggled with dyslexia and dyscalculia as a child



#### Henry Winkler

Actor, comedian, director, and producer who has dyslexia and has said that his trouble reading was a big reason for going off-script



Jennifer Aniston

### **Conditions considered neurodiverse also include:**

- Dyspraxia = Affects 5-6% of school aged children and up to 10% of population
  - Developmental Coordination Disorder
  - Kids and adults with this may have problems with the mechanics of dressing, writing, drawing, or grasping small objects

'[l] sometimes still ha[ve] trouble tying [my] shoelaces.'

--Daniel Radcliffe, Actor (Harry Potter Series and more)



www.mayoclinic.org; www.cdc.gov; my.clevelandclinic.org; www.nhs.uk; https://gitnux.org/neurodiversity-statistics/; https://exceptionalindividuals.com/about-us/blog/5-famous-people-who-have-dyspraxia/

### **Dyscalculia = Affects 1 in 20 people in the United Kingdom; 3-7% in Germany**

 Learning disorder that affects a person's ability to understand number-based information and math



**Bill Gates** 

Founder of Microsoft who has dyscalculia



Mary Tyler Moore Actress who has dyscalculia

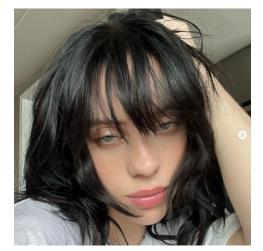
34

## **Conditions considered neurodiverse also include:**

Tourette Syndrome = ~1.4-3.0% of US adults (1.4-3.4 million people). A neurological condition where people have tics, or sudden twitches, movements, or sounds done repeatedly that are not easily controlled



"In a 2021 tweet, Emmynominated actor **Seth Rogan** shared that he has 'very mild' Tourette syndrome that manifests as **twitching**."



**Billie Eilish**, Grammy and Oscar award winning singer/songwriter

"wiggling [my] ears back and forth, raising her eyebrows, clicking [my] jaw, and flexing [my] arms"



Jamie Grace, Grammynominated singer and songwriter

" blinking my eyes to hitting my upper chest to making "ah!" and "uh!" sounds to my arms and legs bending repeatedly"

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## **Conditions considered neurodiverse also include:**

Dysgraphia – Prevalence is unknown. Estimated 5-20% of people in the US Difficulty turning thoughts into written language despite exposure to adequate instruction and education



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## Why do we have neurodiversity?

### Working hypotheses:



- Neurodiversity: part of human genetics and evolution as a species
- Gene variants associated with neurodiverse conditions "have and will continue to have advantages for society"
- Hypotheses: gene variants linked to ADHD or autism may have been selected for because of associations with adventure seeking, heightened vision, taste, smell, and memory

## Why do we have neurodiversity?

## Working hypotheses:



# How do we reconcile different perspectives on neurodiversity that can range from:

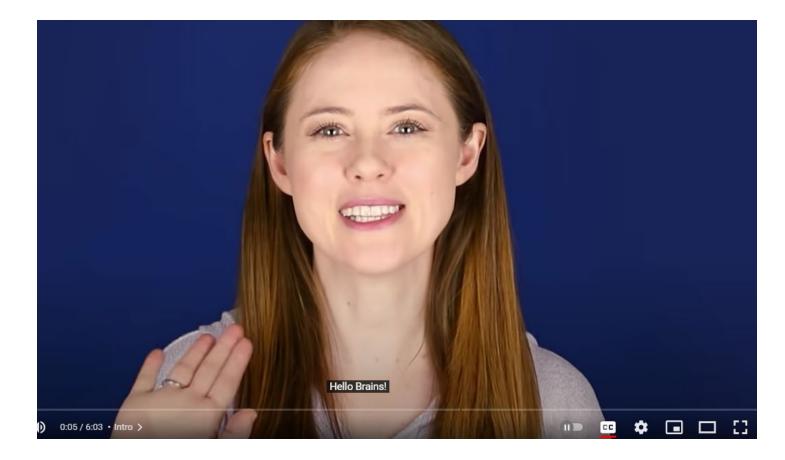
## "Hey, we're all wired a bit differently, no big deal" To "Anyone who is not neurotypical has a disability"



## Neurodiversity and the Social Model of Disability

## Video: [0:05 to 3:47]

https://www.youtube.com/watch?v=ALJ3CFRRZpo



https://www.youtube.com/watch?v=ALJ3CFRRZpo

# Using "Neuro Cards" to explore Neurodiversity, the Social Model of Disability, and US! (at TARC/RAI)

- Watch the video:
- In our Small Groups: Facilitator and no more than 7 other people (ideally maximum of 8 people per group)
- Facilitator
  - Identify the person who will speak up for the whole group to larger crowd
  - If no one volunteers, then Facilitator will be the default reporter
- Use terms described in "Neuro Cards : Exploring Neurodivergence" to guide discussion of concepts introduced in the introduction and video



#### NEURO CARDS: Exploring Neurodivergence Designed by Newglade Counselling (Therapist in the UK)

#### Logistics for: Neurodiversity, the Social Model of Disability, and US! (at TARC/RAI)

- The cards cover terms related to neurodiversity that span 4 broad categories:
  - #1: Interactions with Others in Social Settings
  - #2: Experiencing and interacting with the environment
  - #3: Information Processing
  - #4: Self-Identity

• Each group will have **20 minutes to share experiences within the group** as they feel comfortable and to discuss their concept category

#### Logistics for: Neurodiversity, the Social Model of Disability, and US! (at TARC/RAI)

- We will show a slide that lists the broad concept terms for everyone to see
  - 4 broad concept categories and associated terms also attached to end of packet
- After small group discussion, we will reconvene so each group can share their insights, about 1 to 2 minutes (max) per group
- SHORT Qualtrics Survey Questionnaire to answer at the end

## Neurodiversity, the Social Model of Disability, and US! (at TARC/RAI)

- We have distributed **handouts** that have the definitions of the broad concept terms on display during discussion time
- Handouts also have a list of potential questions for discussion. You don't necessarily have to get through all of them and your conversation may diverge from the questions. That's okay. We want to foster dialogue
- Challenge: Whether you identify as neurotypical or neurodiverse, challenge yourself to think about instances or experiences where you or a close friend or family member might have related to the concept up for discussion

## Neurodiversity, the Social Model of Disability, and US! (at TARC/RAI)

#### **#1) Interacting with others in social settings**

- Communication
- Masking / Burnout / Chameleon

#### #2) Experiencing and interacting with the environment

- Sensory processing
- Square Peg in a Round Hole

#### **#3) How you process information**

- Many Tabs open
- Thinking Outside the Box / Seeing the Big Picture

#### <u>#4) Self-Identity</u>

- Identity
- Self-esteem

### Interacting with others in social settings #1

#### **DEFINITIONS BELOW.** Please turn to next page for discussion questions.

#### Interacting with others in social settings

#### **Communication : Means of sending and receiving information**

People use different communication styles which can lead to misunderstandings. E.g. neurotypical people may use ambiguous language or sarcasm to make a point which neurodivergent people can find difficult to interpret. Neurodivergent people may prefer alternative methods of communication.

#### Masking / Burnout / Chameleon:

#### Masking: Hiding yourself to appear more neurotypical

#### Chameleon: Changing yourself in order to blend in

People who mask have often studied body language and expressions for many years in order to mimic them – good at reading people as a result. Often done unconsciously especially when neurodivergence is undetected. Being able to blend into different environments to fit in. Often hyper vigilant to others' body language, tone or mood. Good at "reading the room". Can be exhausting and lead to burnout, which a point of exhaustion reached from being overwhelmed. Burnout can involve mental, emotional, or physical exhaustion and can be reached after a short time or after many years of masking and keeping things under "control."

## Interacting with others in social settings - #1

#### It is okay if you don't get to all the questions. We have several listed to spark dialogue.

#### Interacting with others in social settings – Potential discussion Questions:

- Are you able to express when a communication style is not effective for you?
- What barriers prevent you from communicating effectively?
- How do you think it would feel when you enter an environment or social setting where you feel you have to mask?
- How does it make you feel that colleagues, friends, or family feel they need to mask to get through a day?
- Do you feel that you ever have to mask?
- Do you ever enter situations where you feel that you have to make extra effort or be be very careful about paying attention to body language, tone, mood, "reading the room"?
- If one feels the need to change or adapt to different people and environments, how does that affect their perception of the "real them?" the "real you?"
- How can masking lead to burnout? What do you need to prevent you from reaching burnout? What do you need to help you recover from burnout?

## **Experiencing and interacting with the environment- #2**

#### **DEFINITIONS BELOW.** Please turn to next page for discussion questions.

#### **Experiencing and interacting with the environment**

#### Sensory processing: Being sensitive to touch, noise, texture, lights etc

Taking in a large amount of information all the time. Can be via all the senses and induce feelings of pain, anxiety or panic. Can also include sensory seeking behavior, when you look for more sensory input.

#### Square Peg in a Round Hole : Feeling like you don't fit in

Neurodivergent people can often feel they don't fit in. This is often thought to be due to the systems which are created for (and by) neurotypical people, leaving little room for alternative ways of thinking or being.

## **Experiencing and interacting with the environment- #2**

It is okay if you don't get to all the questions. We have several listed to spark dialogue. Experience and interacting with the environment

- Do your environments accommodate sensory overload or sensory seeking?
- If not, how does this make you feel (exhausted, frustrated, shut down?)
- What strategies do you use to cope?
- Also, what accommodations would you recommend?
- When are you most aware of feeling like a square peg?
- Are there certain contexts in which this feeling is exacerbated?
- Does one need to fit in everywhere?
- Are there ways that a "round hole" could adapt to fit both "square" and "round" pegs?

## How you process information - #3

**DEFINITIONS BELOW.** Please turn to next page for discussion questions.

#### How you process information

#### Many Tabs open: Having lots of thoughts on the go simultaneously

Being able to have many thoughts at once is sometimes described as having many tabs open. As a result, tend to be able to problem solve in an abstract way. Flitting quickly between thoughts like this can be exhausting and hard for others to keep up.

#### vs. Object Permanence: Ability to know/ to remember an object exists if you can't see it

Neurodivergent people may sometimes have difficulty with this. It can relate to people or objects or tasks that need to get done, where you may need to keep things out on display in order to remember them.

#### Thinking Outside the Box : Able to think in an abstract way

Innovative, good at problem solving and seeing things from another perspective. Can often see the big picture when others can't or, conversely, can see the small details which others miss

#### Seeing the Big Picture : Being able to see the wider view of something

Good at being able to see the wider scale implications of a project or task. Sometimes may miss the smaller details.

#### It is okay if you don't get to all the questions. We have several listed to spark dialogue.

#### **How You Process Information**

- When do you feel the most comfortable thinking outside of the box?
- Are there factors that limit your ability to see the big picture?
- When is "Thinking outside the box" considered a positive?
- When is it considered "outside the norm?"
  - While many can see innovation coming from Thinking outside of the box and the "norm" is to say, "Let's all think outside the box", but in the neurodivergent world it can sometimes be a place where people laugh, totally discard, and diminish the idea or demeaning the person since they may seem different or untimely.
- How do you receive and process ideas, suggestions, and problem-solving techniques, especially when it looks different from your method?

## Self-Identity - #4

#### **DEFINITIONS BELOW.** Please turn to next page for discussion questions.

#### Self-Identity

#### Identity : The distinguishing character of a person

Often tied up with labels, stereotypes and self-worth. Identity can be difficult to determine for many, especially if masking has been happening for some time.

#### Self-esteem: Your opinion of your own value and worth

Many neurodivergent people can have low self esteem due to years of masking to fit in within a neurotypical world and being made to feel not good enough.



## Self-Identity - #4

#### It is okay if you don't get to all the questions. We have several listed to spark dialogue.

#### Self-Identity

- How do you think that the way one processes information, interacts with the environment and one's social circles, and how one communicates:
  - Impacts identity or personality? Or how you define your authentic self?
  - What about the impact on one's opinion of their own value and worth?
  - If one feels the need to change or adapt to different people and environments, how does that affect their perception of the "real them?"

## Large Group Sharing Time ~ 15 minutes

# Conclusions

## Neurodiversity and its impact

- The concept that there is natural variation in the human brain that leads to differences in how we think and behave
- It impacts our patients, our study volunteers, our families, colleagues, and ourselves
- Neurodiversity Movement neurological differences among people should be recognized and respected

## Conclusions

## Social Model of Disability –

- Instead of focusing on what a person can or cannot do (their impairments), we focus on barriers that person faces within society – environmental & physical barriers, societal attitudes, etc. – and whether and how to adjust our external environment to remove barriers
- Question potential assumptions about the abilities and challenges of neurodivergent individuals

# THANK YOU FOR YOUR PARTICIPATION!

## Thank you for your participation!

What did you learn? And what did we miss? Please give us feedback using this Qualtrics survey

#### **QUESTIONS:**

- Before participating, how would you rate your knowledge of neurodivergence? (1: No knowledge, 5: Expert knowledge)
- After participating, how would you rate your knowledge of neurodivergence? (1: No knowledge, 5: Expert knowledge)
- How relevant did you find the information about neurodivergence to your personal or professional life? (1: Not relevant, 5: Very relevant)
- Free response: What assumption that you may have held about neurodiversity was challenged by this activity?
- Free Response: Any additional feedback?



https://unc.az1.qualtrics.com/jfe/form/SV\_0STUVultAekRUxM

## All submissions are anonymous 57