

How can we use an understanding of the neurodiversity movement to develop socially valid supports for autistic people?

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**Resources and
Education on
Autism as
CUNY's
Hallmark**



The FAR Fund

Neurodiversity:



The Spice of Life!

by Rays



Please introduce yourself in the chat

1. What are your name and pronouns?
2. Why did you come to this webinar?
3. What is a question you currently have about the neurodiversity movement?

Learning Objectives

1. Discuss what the neurodiversity movement is and associated controversies
2. Examine autistic and non-autistic stakeholders perspectives about intervention goals
3. Explore factors that impact the mental health of autistic young adults
4. Understand why an intersectional approach to developing autism supports is needed
5. Learn how we can collaborate to make society more supportive of neurodivergent people

Take home points

- Structural barriers oppress neurodivergent people;
- Proponents of the neurodiversity movement advocate for supports but oppose normalization;
- Social connections help protect the mental health of neurodivergent people;
- Neurodivergent-led care and anti-stigma initiatives are needed but must be developed mindfully.

Medical Model

The “Medical Model” views autism and other conditions:

- In terms of deficits and impairments
- As “diseases” to try to cure
- Attempts to normalize “abnormal” people

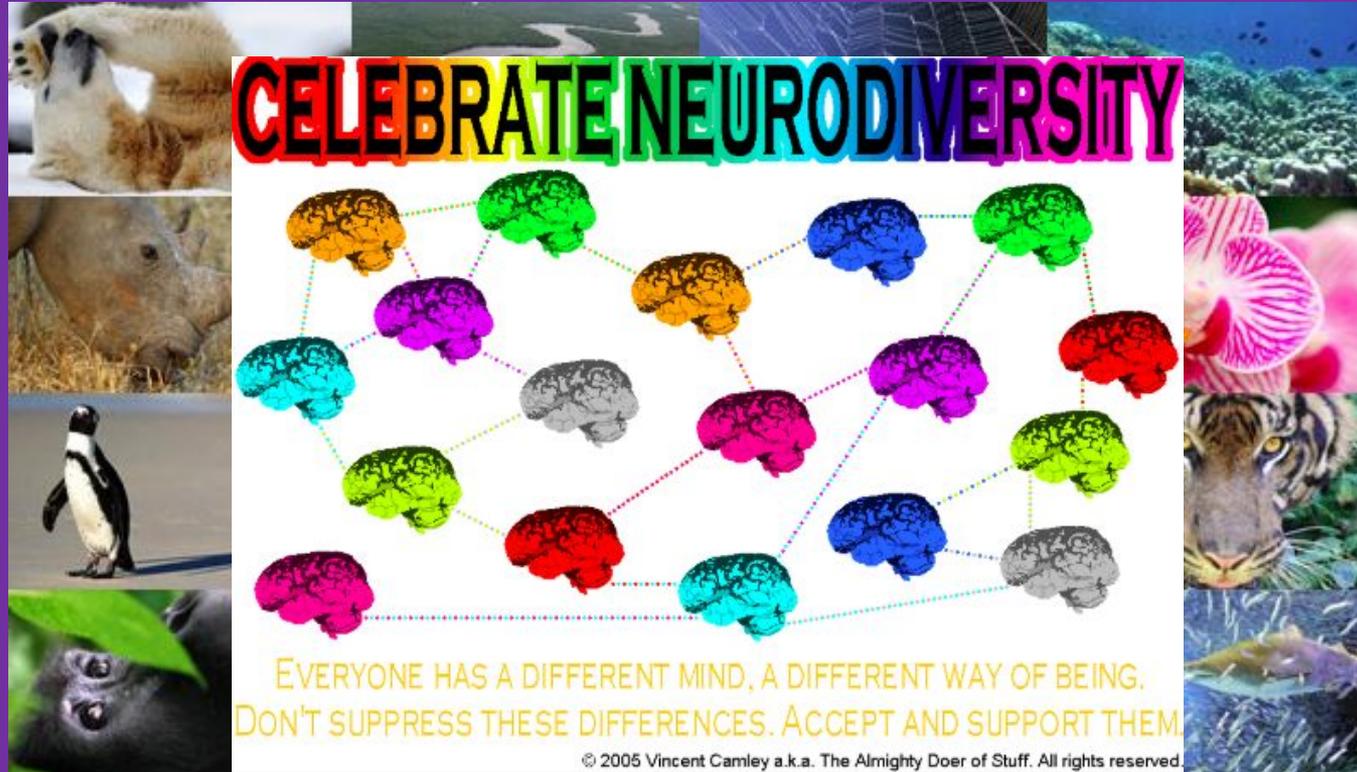


What is neurodiversity?

- **Neurodiversity (ND)** is the diversity of all brains and minds (Singer, 2017; Blume, 1998).



What is the neurodiversity paradigm?



CELEBRATE NEURODIVERSITY

EVERYONE HAS A DIFFERENT MIND, A DIFFERENT WAY OF BEING.
DON'T SUPPRESS THESE DIFFERENCES. ACCEPT AND SUPPORT THEM.

© 2005 Vincent Camley a.k.a. The Almighty Doer of Stuff. All rights reserved.

What is the neurodiversity paradigm?

A **viewpoint** about neurodiversity that includes the following key principles:

- **Neurodiversity** is a natural and **valuable form of human diversity**
- The idea that there is one “**normal**” type of brain is an unhealthy, culturally constructed **fiction**
- Similar dynamics manifest in response to neurodiversity as to other forms of diversity, including **power inequalities** or embracing diversity as a source of creative potential.

What is the neurodiversity movement?



What is the neurodiversity movement?

- A **social justice movement** that seeks civil rights, equality, and **full societal inclusion** for **neurodivergent** people:
 - Rejects “normal” as a treatment goal or reality
 - Seeks supports for adaptive skills & quality of life
 - Includes diverse groups and perspectives; no unified leader or manifesto
 - Began with autism rights but often seeks to be inclusive of diverse neurominorities
 - *Who the neurodiversity movement represents remains a bone of contention*

What are some key controversies about the neurodiversity movement?

- Baron-Cohen (2019) tried to resolve conflicts between the neurodiversity movement and the medical model by suggesting that the neurodiversity approach works well for neutral “differences”, but that a medical model is needed to address “severe challenges.”
- This represents a key misconception about the neurodiversity movement, that it is **identical** to the social model, or that disabilities are **only** disabilities because of societal factors (e.g., lack of accessibility).

From: “Clearing Up Some Misconceptions about Neurodiversity”

- Bailin, an autistic self-advocate, responded by pointing out that the neurodiversity movement includes all kinds of autistic people, including those who might be described as having “severe challenges.”
- “When we talk about “not pathologizing autism,” we don’t mean “pretending autistic people don’t have impairments.”
- **But we also don’t assume that ... differences are always problems...**”

Please share in chat:

- How well do existing supports match what community members want?
- Please share a rating from **0 to 100%**

What do community members and neurodiversity advocates want?



Steven Kapp



Lynnette Hersh



David Chang



Susan Rivera

What do community members and neurodiversity advocates want?

Online survey study with responses from 501 stakeholders

	Parents	Autism Researchers	Professionals, Educators, Clinicians	TOTAL
Autistic	51	41	33	275
Non-autistic	108	59	87	226
TOTAL	159	100	120	501

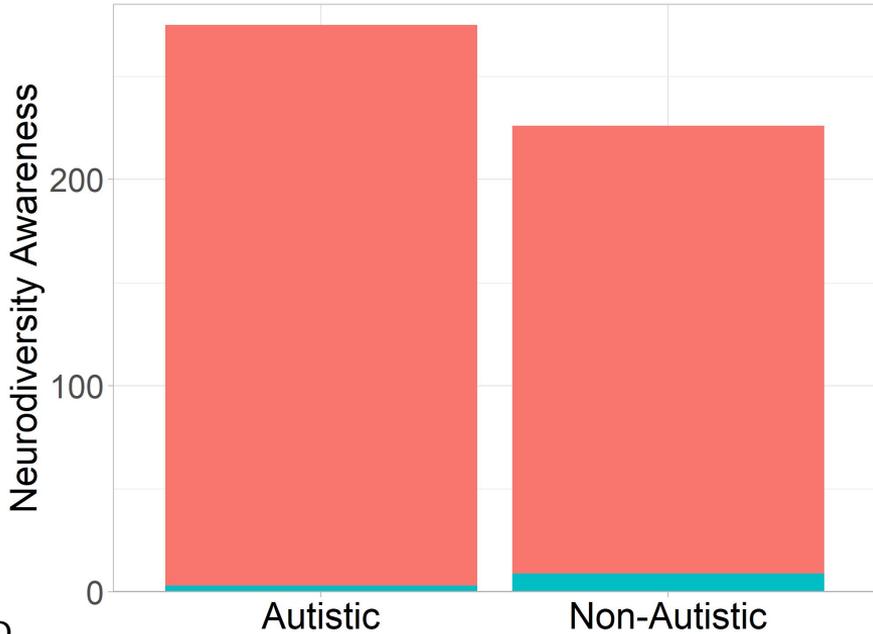
*not mutually exclusive

Views on NDM

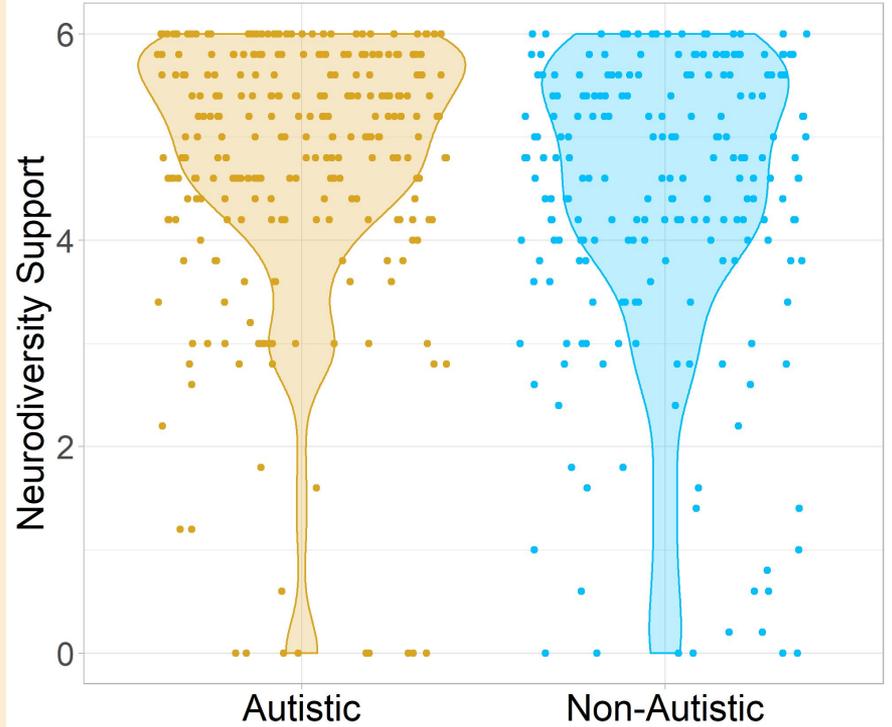
(scale adapted from Nario-Redmond et al., 2013)

Neurodiversity Awareness

Have Heard Haven't Heard



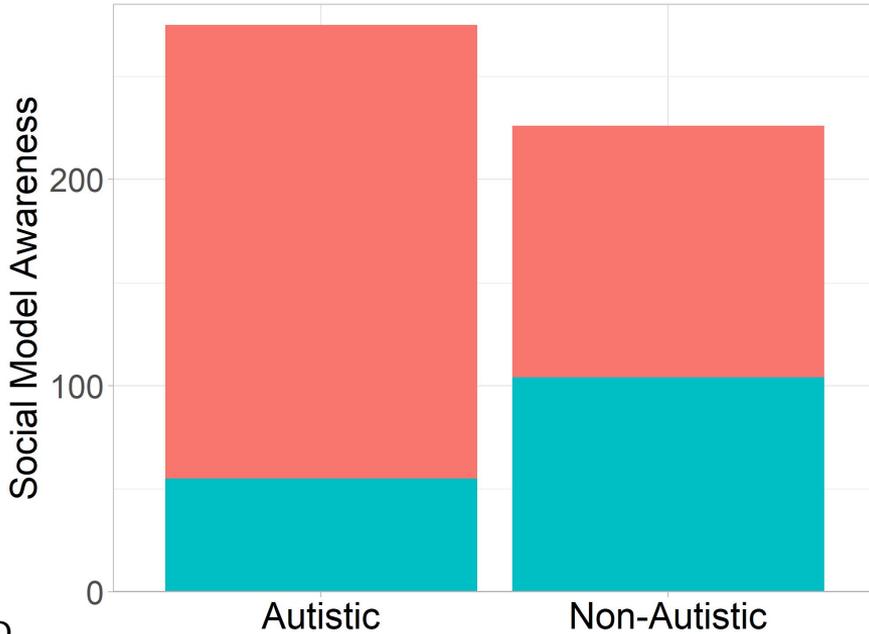
Neurodiversity Support



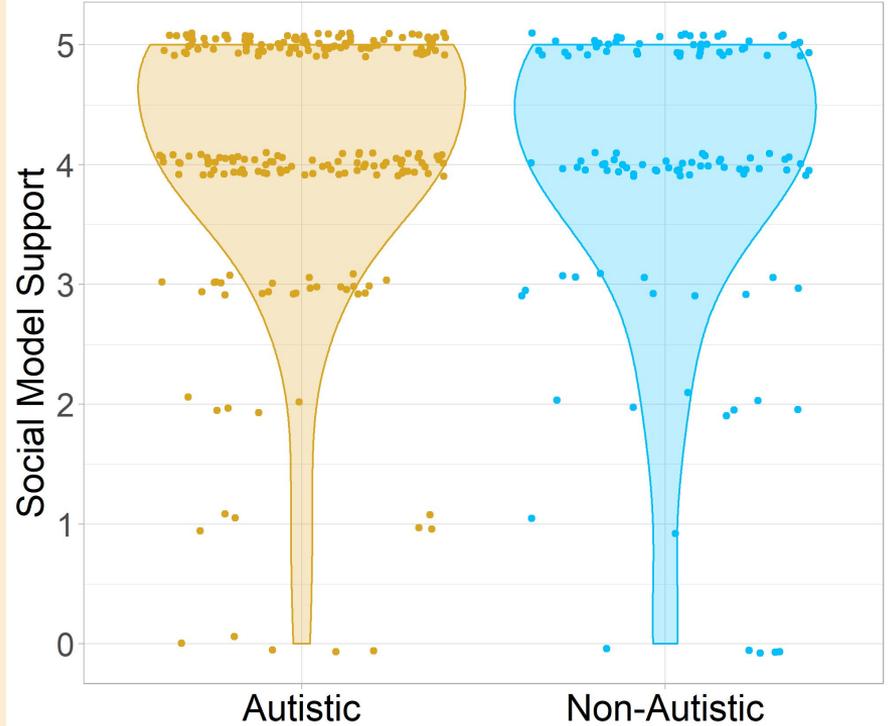
Views on Social Model

Social Model Awareness

Have Heard Haven't Heard



Social Model Support



5 types of intervention goals

Normalization

e.g., “Promoting eye contact with others is a good intervention goal.”

Adaptive Skills

e.g., “Building interpersonal skills is a good intervention goal.”

Well-Being

e.g., “Reducing depression levels is a good intervention goal.”

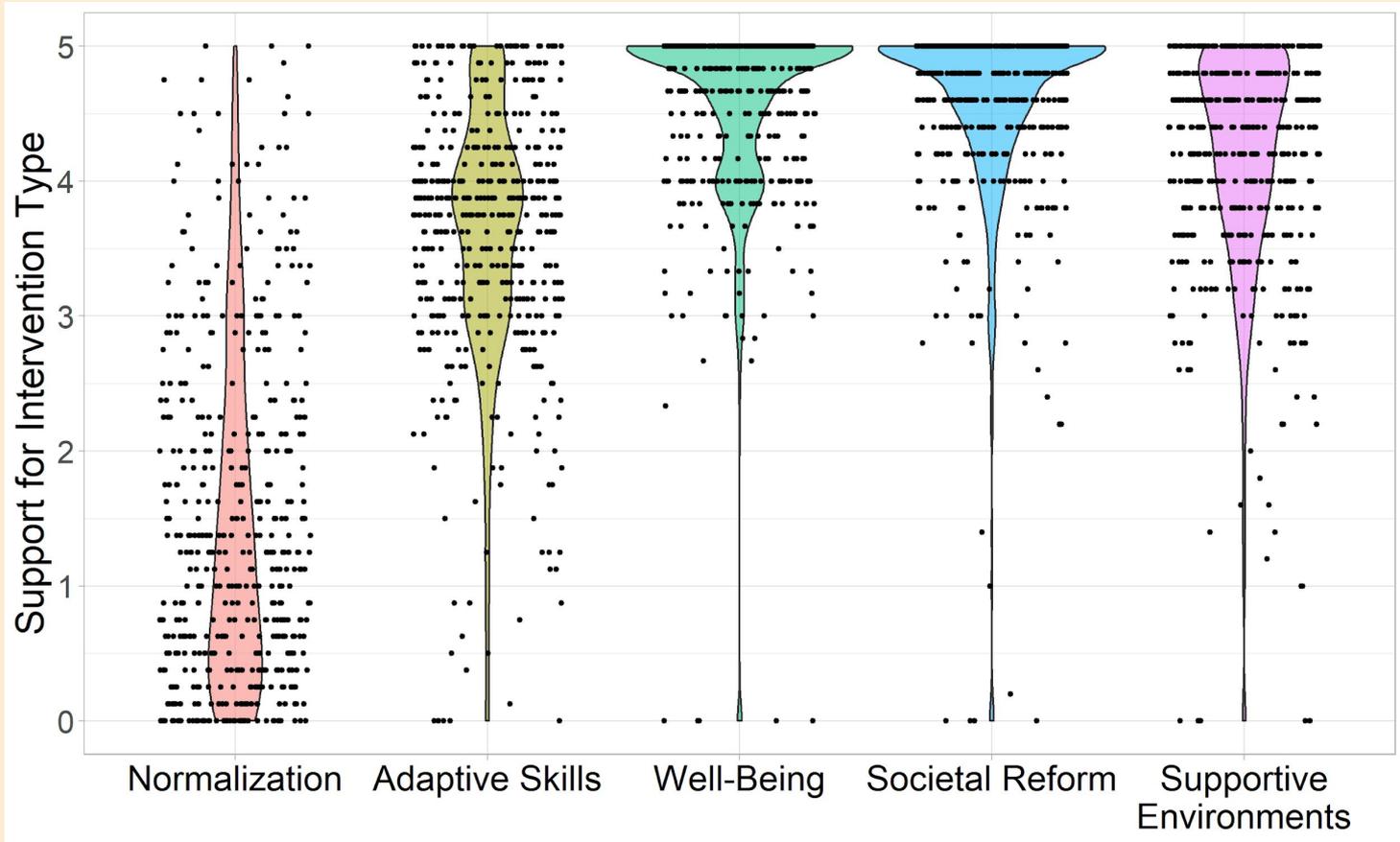
Societal Reform

e.g., “Educating non-autistic people about how to communicate better with autistic people is a good intervention goal.”

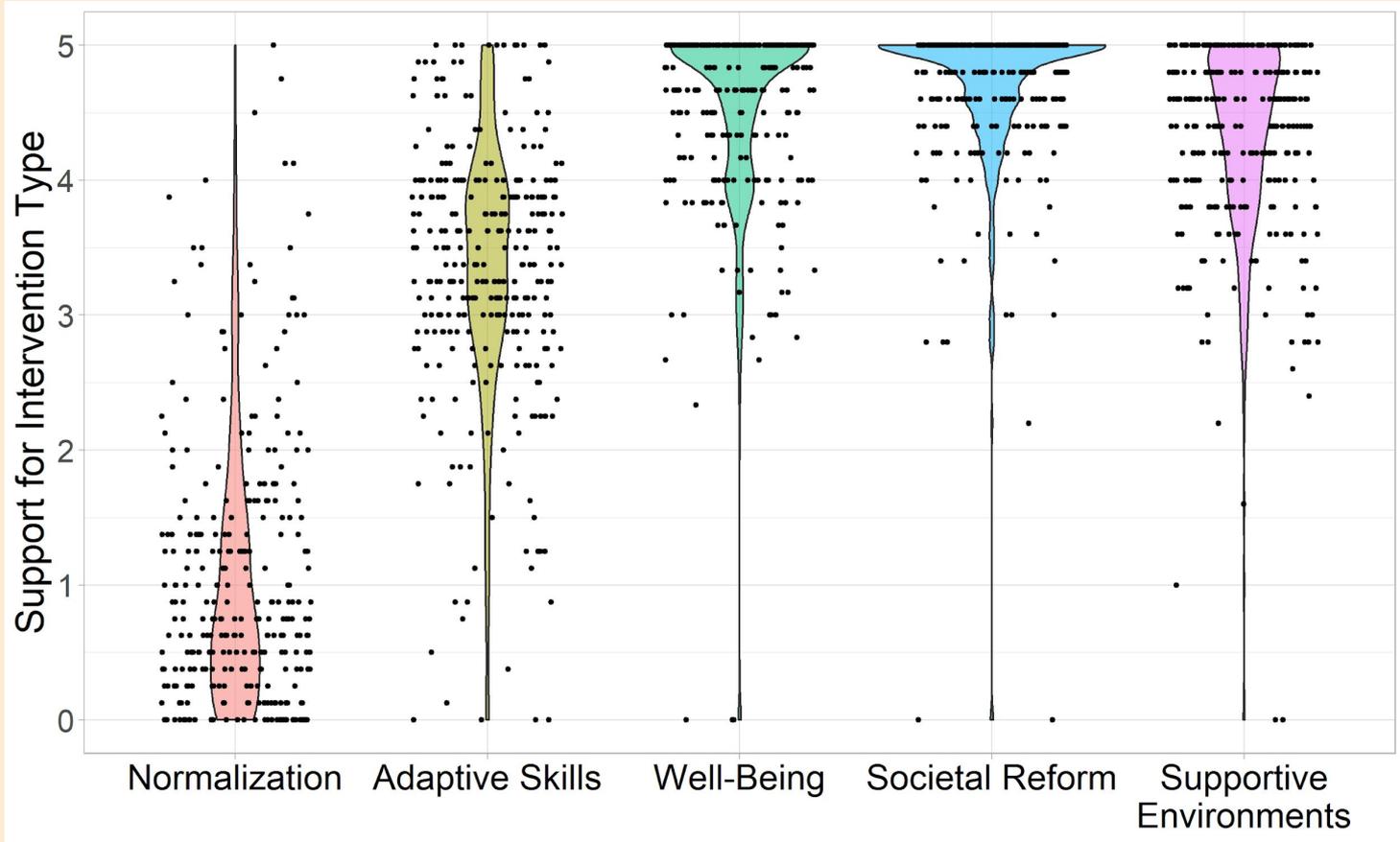
Supportive Environments

e.g., “Eliminating overwhelming sensory stimuli from autistic people’s environments is a good intervention goal.”

What is preferred?



Social model supporters only:



Social model & intervention

Social model supporters clearly **DO NOT** think we should focus **ONLY** on society

Instead, social model supporters believe interventions to teach individuals useful skills can be helpful

This misunderstanding of advocates' goals has led to much confusion and controversy!

(not to mention that some neurodiversity advocates don't even support the social model)

How are we doing?

“...research focused primarily on outcomes associated with the core symptoms of ASD: social, communication, and challenging behaviors... Outcomes...such as vocational skills and mental health appeared infrequently...”

(Wong et al., 2014)

Table 6. Outcomes Identified In Studies	
Outcomes related to	Studies (n)
Social Skills needed to interact with others	165
Communication Ability to express wants, needs, choices, feelings, or ideas	182
Challenging/Interfering Behaviors Decreasing or eliminating behaviors that interfere with the individual's ability to learn	158
Joint Attention Behaviors needed for sharing interests and/or experiences	39
Play Use of toys or leisure materials	77
Cognitive Performance on measures of intelligence, executive function, problem solving, information processing, reasoning, theory of mind, memory, creativity, or attention	15
School Readiness Skills Performance during a task that is not directly related to task content	67
Pre-Academic/Academic Performance on tasks typically taught and used in school settings	58
Motor Movement or motion, including both fine and gross motor skills, or related to sensory system/sensory functioning	18
Adaptive/Self-Help Independent living skills and personal care skills	55
Vocational Employment or employment preparation or relate to technical skills required for a specific job	12
Mental Health Emotional well-being	1

What do you think contributes to heightened depression in autistic communities?

Please share what you consider to be the most important factor in the chat

Predictors of Depression Across Autistic and Non-autistic Students' First Semester of College

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Rowan University, Glassboro, NJ

Introduction

- Autistic adults are **~4x** more likely to experience depression compared to non-autistic adults (Hollocks et al., 2019; Hudson et al., 2019)
 - Depression prevalence: current ~23% and lifetime ~37%
- Mental health is a research priority for autistic adults (Benevides et al., 2020; Crane et al., 2019; Pellicano et al., 2014; Van Hees et al., 2015).
- College transition may be a particular vulnerability point (Bailey et al., 2020; White et al., 2016).



Predictors of Depression: Negative Repetitive Thinking

- **General population**

- Prospectively *predicts* depression, anxiety, suicidality, and other negative health outcomes
(Nolen-Hoeksema, 1991, 2000; Thomsen et al., 2004; Watkins, 2008; Miranda & Nolen-Hoeksema, 2007)
- *Maintains* depression and anxiety (Abela & Hankin, 2011; Nolen-Hoeksema, 1991)

- **Autistic Adults**

- Increased in autistic adults (Gotham et al., 2018; Crane et al., 2013)
- Cross-sectionally related to depression (Keenan et al., 2018; Rieffe et al., 2014)



Predictors of Depression: Social Dissatisfaction

- **General population**

- Social support as protective factor (Sarason et al., 1997; S. E. Taylor, 2007)
- Loneliness predictive of depression (Hawkley & Cacioppo, 2010; Cacioppo et al., 2006; Wei et al., 2005)

- **Autistic adults**

- Autistic students tend to feel less connected to their peers and university (Van Hees et al., 2015; Casagrande et al., 2020).
- Social connection is related to subjective wellbeing (Bailey et al., 2020; Smith & White, 2020)
- Poor social support is cross-sectionally related to loneliness and depression (Han et al., 2019)



Current Research: Hypotheses

Incoming college students who report ...

Greater negative repetitive thinking will report **increased depression symptoms** over their first semester, compared to those with lower average repetitive thinking.

Lower social satisfaction in biweekly reports will experience **greater depressive symptoms** over the semester.

- This effect will be stronger for those who reported greater baseline capacity for social reward.

We hypothesize no difference in the model of these mechanisms across autistic and non-autistic student groups, but a **higher proportion of autistic students will exhibit repetitive negative thinking** and **low social satisfaction**, as well as **greater depression scores** on average.



Participant demographics and baseline questionnaire results.

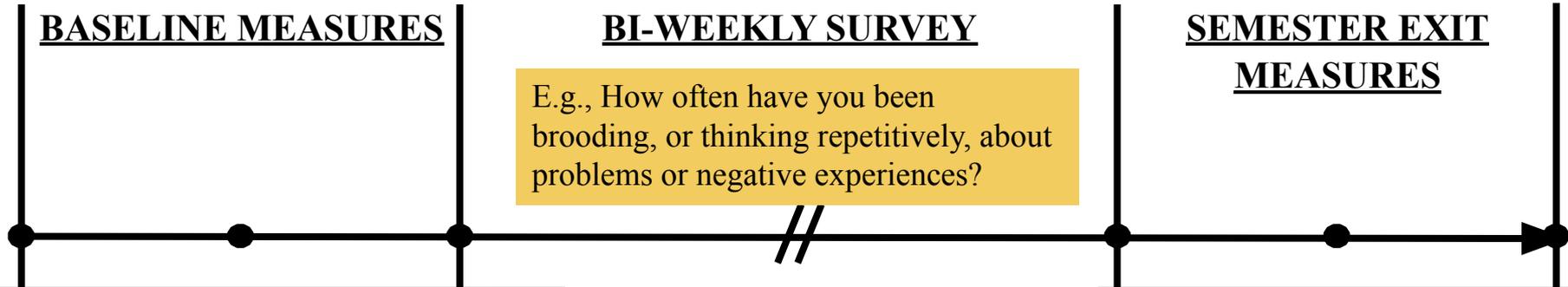
Mean (SD) Range	<u>Non-autistic</u> <i>n</i> = 60	<u>Autistic</u> (clin dx. or self ID) <i>n</i> = 36
Age in Years	19.42 (3.46) 18.0 – 39.0	20.78 (5.95) 18.0 – 43.1
Gender (% F/Nonbinary or Other)	48/10%	41/19%
Non-white/Hispanic	47%	31%
Least Educated Parent (% HS or Less)	38%	33%
SRS-2 (t score)	53.83 (8.31) 39-73	63.50 (10.24) ** 42-85

*Note: SRS-2 = Social Responsiveness Scale, Second Edition; ** = significance at the $p < 0.001$ level.*



Methods

All measures administered via REDCap surveys online (no in-person participation required)



BASELINE MEASURES

BI-WEEKLY SURVEY

SEMESTER EXIT MEASURES

E.g., How often have you been brooding, or thinking repetitively, about problems or negative experiences?

Completed within two weeks of start semester

- Dx history & Autistic traits
- Mental health (dep/anx)
- Physical health
- Repetitive thinking
- Social satisfaction
- Attributional style

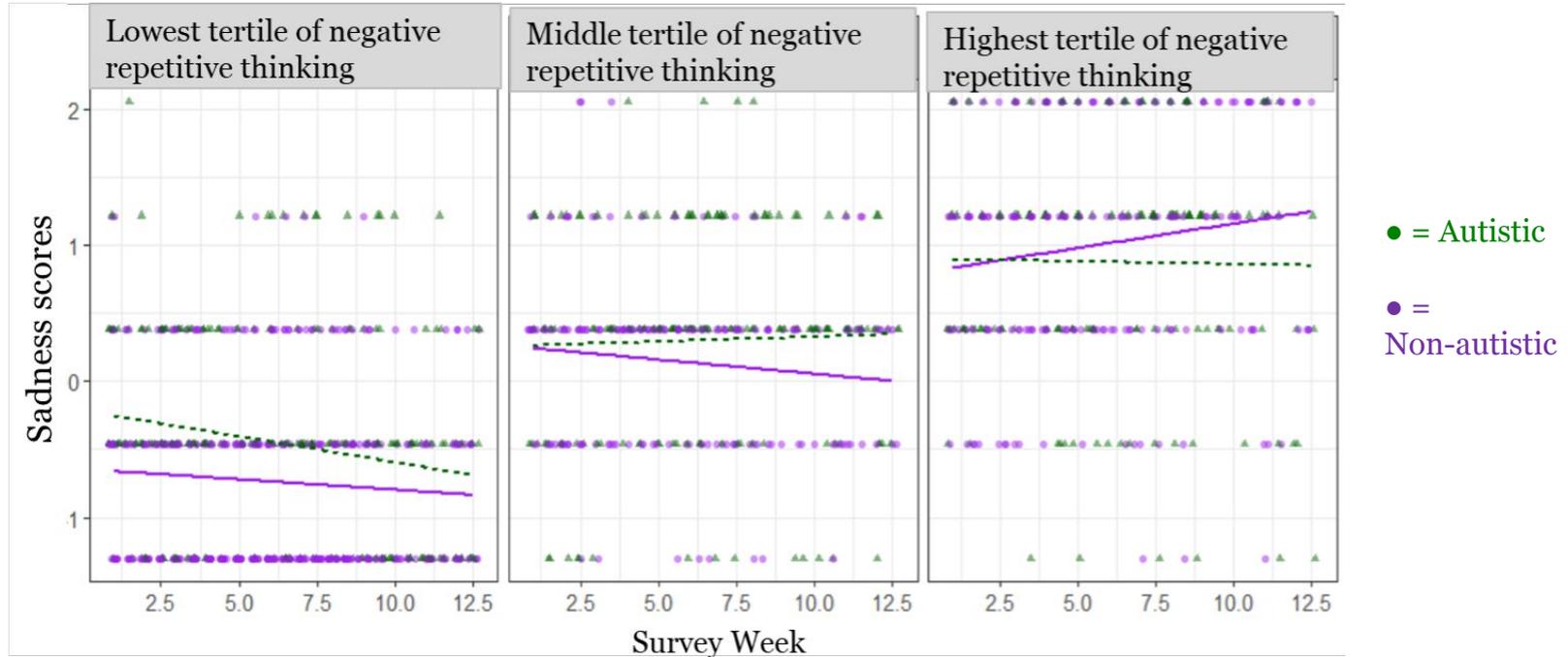
11-question survey,
2x/week throughout semester

- Sad, anhedonia, anx
- Repetitive thinking
- Social engage./satis.
- Stress
- Hopefulness

Completed in last two weeks of semester; similar to baseline



Rumination and Sadness

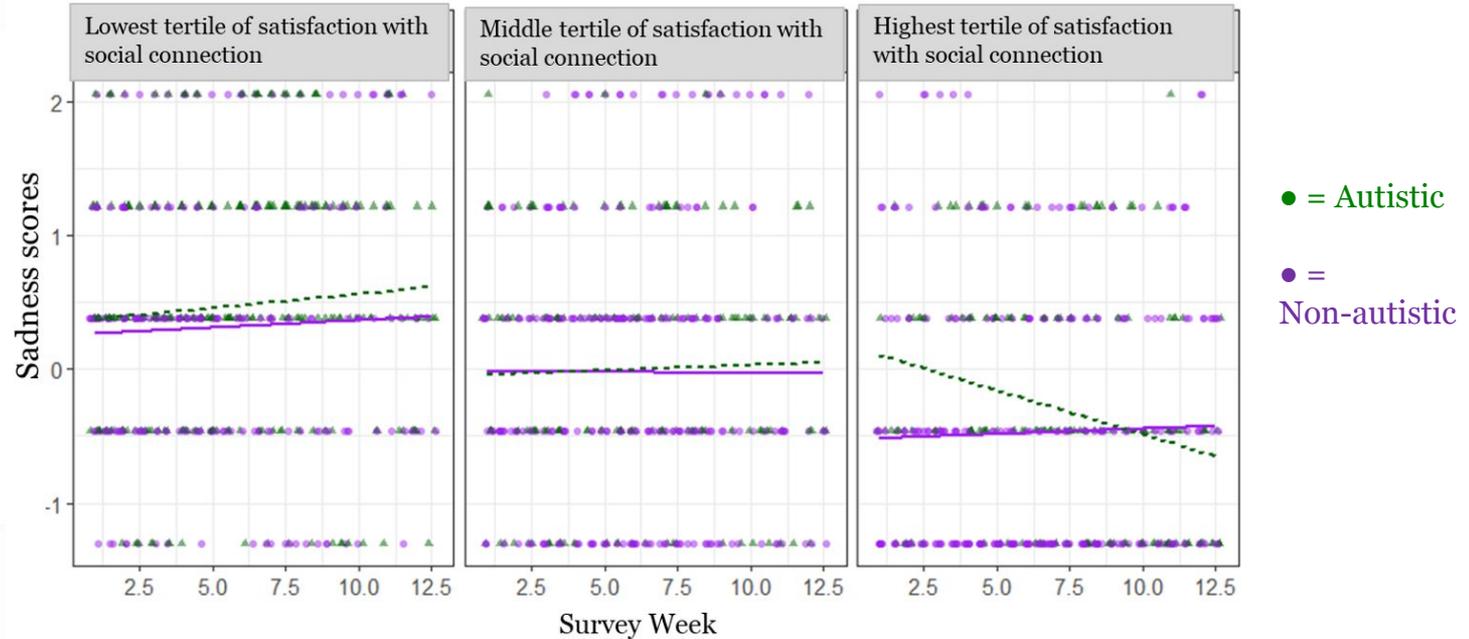


Students with **more negative repetitive thinking** reported **more sadness** across the semester.



Social Satisfaction and Sadness

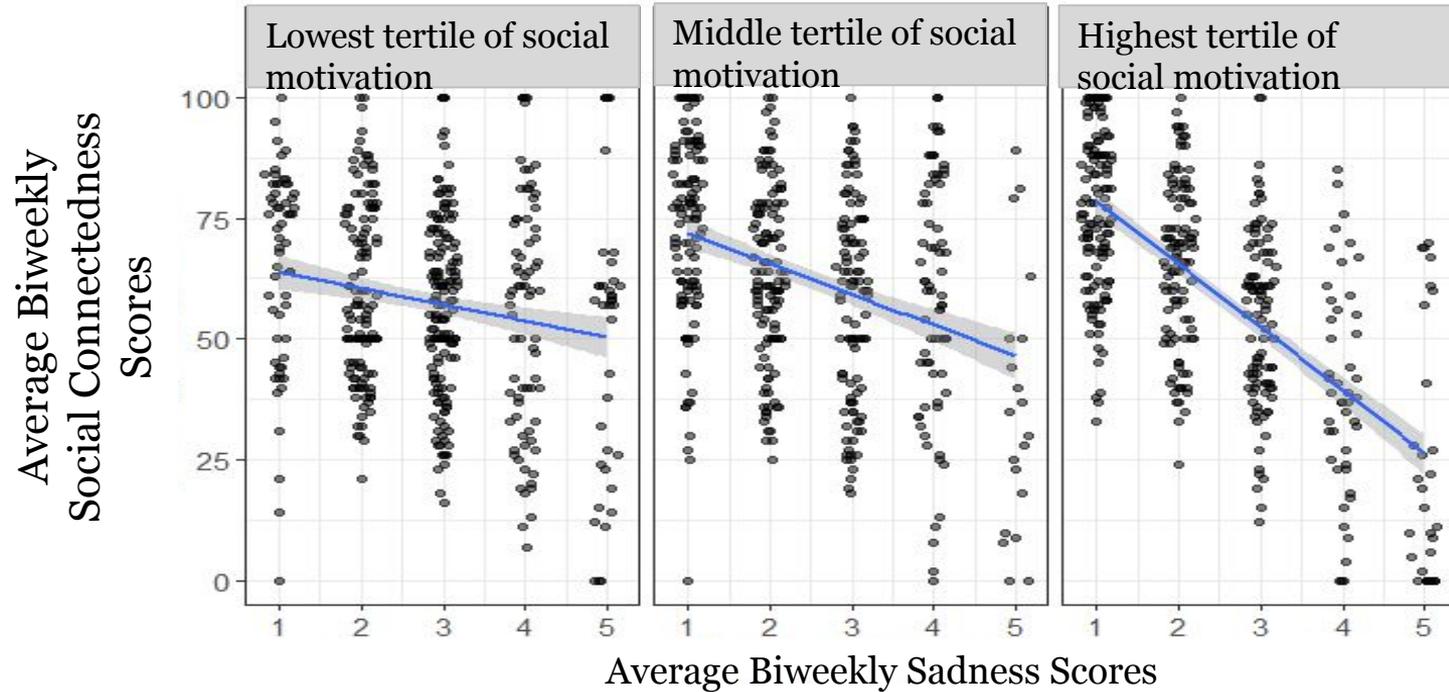
“How satisfied do you feel with your level of social belonging or closeness?”



Students who felt **more socially satisfied** across the semester reported **less sadness** across the semester.



Social Satisfaction and Sadness



Conclusions

- Longitudinal **sadness scores** are significantly related to individuals' average **negative repetitive thinking**, for both autistic and non-autistic students.
- Negative repetitive thinking may be a significant target for prevention/treatment of depression in autistic college students.
- Longitudinal **sadness scores** are significantly related to satisfaction with **social connection**, for both autistic and non-autistic students.



Study Team



Dr. Erin Kang and Rachel McDonald



Dr. Matt Lerner and Talena Day



Dr. Kristen Gillespie-Lynch and
Bella Kofner



Dr. Kaite Gotham, Jared Richards, and Erin McKenney

Questions??

Email Erin: mckenn84@students.rowan.edu



Please share in the chat:

What would be one advantage of having more autistic clinicians?

Importance of Taking a Neurodivergent-Led Approach

Sergey Shevchuk-Hill

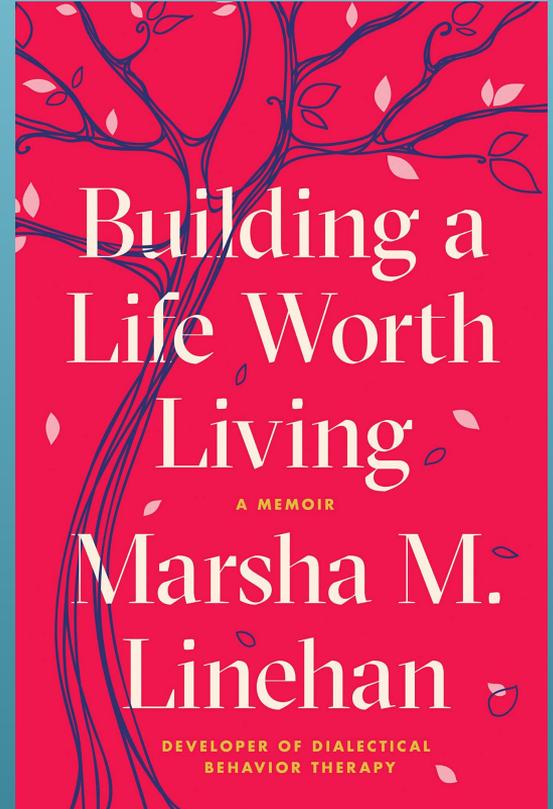
Pronouns: they/them/their

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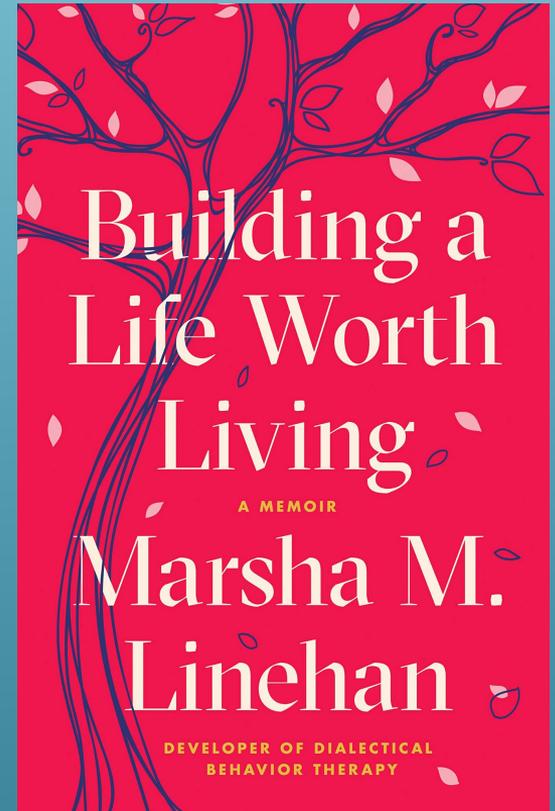
Dialectical Behavioral Therapy (DBT)

- Dr. Linehan developed DBT
 - First evidence-based therapy for Borderline Personality Disorder and suicidality
 - These clients were considered some of the most difficult to work with



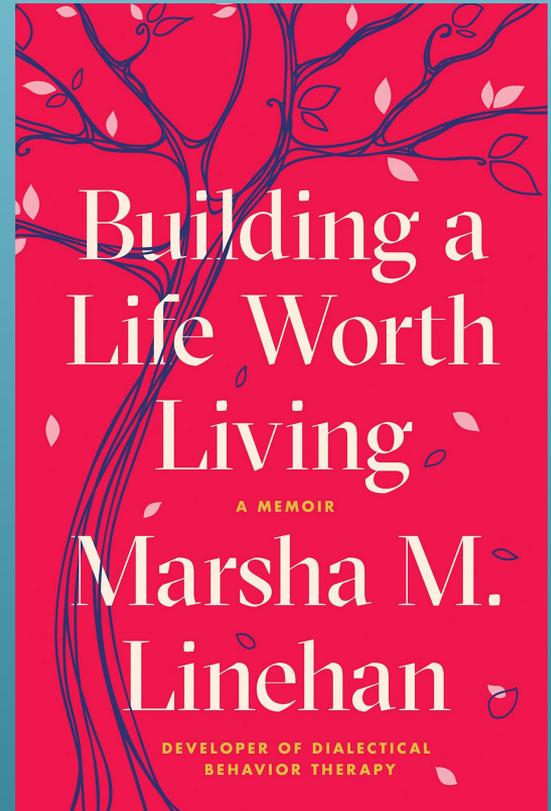
Dialectical Behavioral Therapy (DBT)

- Dr. Linehan developed DBT
 - Based on her experiences with Borderline Personality Disorder
 - Dialectic
 - Accepting self
 - Needing change



Dialectical Behavioral Therapy (DBT)

- DBT impacted other therapies
 - E.g., mindfulness
- One of Dr. Linehan's reasons for publishing her story was how much it would mean to her clients to know that she had gone through experiences similar to their own



Self Injurious Behaviors

- DBT provided a more humanising way of approaching self injurious behaviors
 - Seen as coming from intense emotions
 - Occur when one's only way of coping
 - Can be treated through
 - Harm reduction
 - Emotional regulation

Self Injurious Behaviors

- Autistic people engage in self-injurious behaviors for the same reasons as non-autistic people (Skedy et al., 2019)
 - Same or similar approaches should be used
 - But, autistic people are often treated differently, often with aversive stimuli

Own Voices

- “Nothing about us without us”
- Linehan’s story also provides an example of the impact the perspective of a person with first-hand experience can have

Empathy

- Empathy is the cornerstone of any effective therapeutic approach
- Double empathy problem
 - Differences between neurotypes can make it difficult for people to empathise with each other
 - Can present a barrier for clinicians

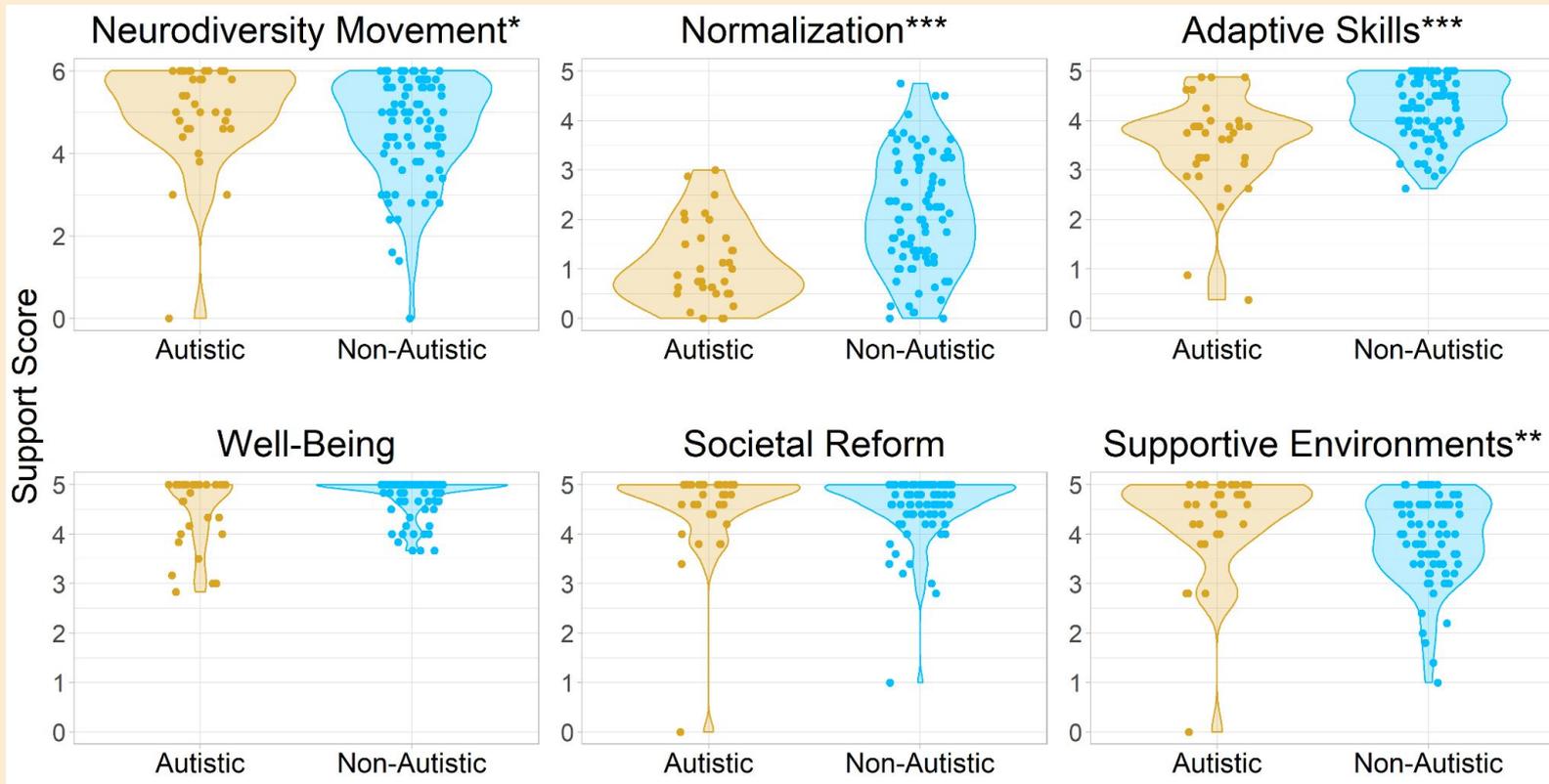
We need more autistic clinicians

- Autistic people trained as researchers and clinicians could have a lot of impact on the field
 - Collaborate and consult with colleagues who are seeing autistic clients
 - Collaborate on developing trainings for non-autistic colleagues
 - Develop new and improve existing supports

We need more autistic clinicians

- It would also allow autistic clients to see themselves reflected in their clinicians
 - Can strengthen the therapeutic alliance
 - Can provide a role model and inspiration
 - Reduce stigma through positive contact between autistic and non-autistic colleagues
 - Shows clients that people like them are not excluded from the field

Autistic and non-autistic professionals



* $p < .05$; ** $p < .01$; *** $p < .001$

Autistic and non-autistic professionals

Autistic professionals less supportive of parents playing leading role in developing intervention goals, $p < .0001$

Autistic professionals also less likely to believe that professionals should play leading role in developing intervention goals, $p < .0001$

Autistic professionals were less supportive of promoting communication by primarily focusing on verbal speech, $p = .009$

Intersectionality

- As we aim to increase neurodiversity in the field we need to make sure we are continuing to increase other types of diversity as well

Intersectionality

- Autistic people often hold other marginalized identities and can experience multiple types of oppression
 - Many autistic people are also LGBTQ+
 - Clinicians need to specialize in both areas
 - Environment needs to be inclusive of LGBTQ+ clients
 - E.g., providing the option to select “non-binary” gender on intake forms

Intersectionality

- Autistic people often have other co-occurring disabilities
 - Practices need to make sure that they don't over-specialize

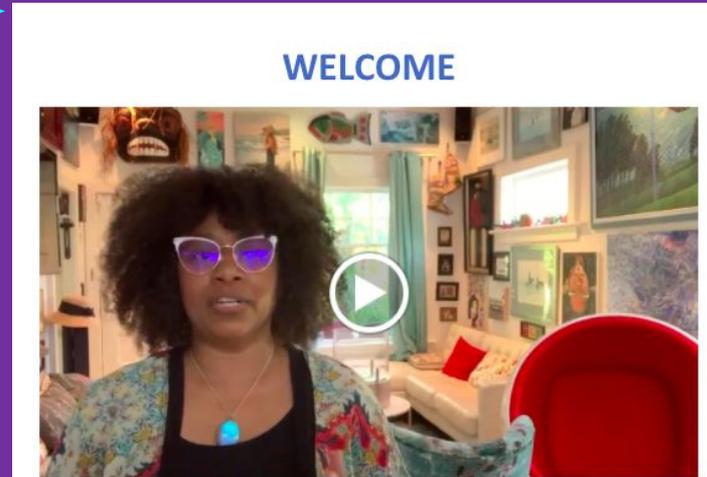
We need to confront ableism

- We need to confront ableism in programs that train clinicians and other professionals
 - E.g., through Universal Design
 - Changes need to happen at all levels
 - Individual classes
 - Individual programs
 - Institutional rules
 - Accreditation requirements

How can we collaborate to make society more supportive of neurodivergent people?

Please share one key strategy in the chat.

Changing society: Participatory trainings



If you want to develop an effective autism training, ask autistic students to help you

Kristen Gillespie-Lynch^{1,2} , Jennifer B Bisson³, Sabine Saade⁴, Rita Obeid⁵, Bella Kofner¹, Ashley Johnson Harrison⁶, Nidal Daou⁷, Nicholas Tricarico¹, Jin Delos Santos¹, William Pinkava¹ and Allison Jordan⁸

Autism

1–13

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Abstract

Autistic university students face stigma. Online trainings have been used to improve *explicit* autism stigma (social distance) and knowledge among university students in different countries. However, autistic university students have not typically been involved in developing such trainings. We developed two autism trainings: a participatory training (developed in collaboration with autistic university students) and a non-participatory training. We evaluated these trainings with undergraduate students in the United States and Lebanon. A pilot study revealed improvements in implicit biases (measured with an Implicit Association Test) and knowledge following both trainings, but no clear benefit of the participatory training in particular. Feedback revealed that participants found the Implicit Association Test tedious, suggesting that it might have dampened effects by boring participants. To increase engagement, we removed the Implicit Association Test and conducted a cross-university training comparison which revealed evidence that the participatory training was more effective than the non-participatory training at improving autism knowledge, explicit stigma, and attitudes toward inclusion. Autistic co-authors coded participant feedback and identified three key themes to guide future training development and adaptation: an (inter)personal element, accessibility, and clarity of information. These studies provide empirical support for the oft-cited, but rarely directed tested, benefits of involving autistic people in research about autism.

Faculty Autism and UD Training

Limited faculty autism understanding may exacerbate autistic students' challenges (e.g., Cage & Howes, 2020).

A participatory team of 8 autistic and 7 non-autistic scholars developed an online training to help university teaching staff understand and appreciate Autism and Universal Design.



Patrick Dwyer



Dr. Dave Caudel



D. Iliana Magiati



Dr. Denise Davidson



Zack Williams



Dr. Eilidh Cage



Dr. Siva priya Santhanam



Dr. Stephen Shore



Dr. TC Waisman



Dr. Kristen Gillispie-Lynch

In this video, an autistic education professor provides insights about UD



“Accommodation is thought of as something that always needs to be created, something that has a cost. This underlines the inherent inaccessibility of nearly all of society: seemingly nothing is ever designed to be accessible in the first place” (Dolmage, 2017, p. 53)

Universal Design (UD) provides multiple pathways for learners to engage with, understand and express understanding of information.

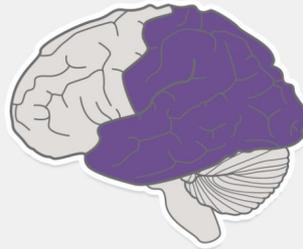
AFFECTIVE NETWORKS:
THE **WHY** OF LEARNING



Engagement

For purposeful, motivated learners, stimulate interest and motivation for learning.

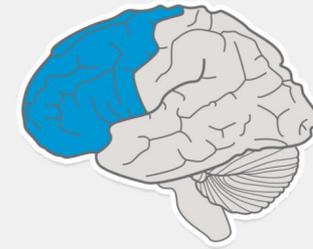
RECOGNITION NETWORKS:
THE **WHAT** OF LEARNING



Representation

For resourceful, knowledgeable learners, present information and content in different ways.

STRATEGIC NETWORKS:
THE **HOW** OF LEARNING



Action & Expression

For strategic, goal-directed learners, differentiate the ways that students can express what they know.

Visual of the three core aspects of UD (engagement, representation, and action/expression): <https://udlguidelines.cast.org/>

Faculty Autism and UD Training: Pre-registered hypotheses

Hypothesis 1: Autism stigma at pre-test will be associated with heightened **social dominance orientation**, being **male**, **lesser autism knowledge**, and being in a STEM field.

Hypothesis 2: Participation will be associated with improved autism knowledge, reduced stigma, and more positive attitudes toward UD.

Methods

The training and assessments were developed using participatory methods involving autistic people in all aspects of its development and research.

University teaching staff completed
online surveys and training

Pre-test survey

Assessed
attitudes about
autism and UD
and use of UD

Two training modules

Module 1 on Autism
Module 2 on UD
Link to Training:
[bit.ly/AutismUD
TrainingFaculty](https://bit.ly/AutismUDTrainingFaculty)

Post-test survey

Assessed
attitudes about
autism and UD
and use of UD

Maintenance survey (1 month after post-test)

Assessed
attitudes about
autism and UD
and use of UD

Participant Characteristics

Number of Participants (<i>N</i>)	98	Teaching experience	
Male/Female/Other	29/64/5	< 1 year	6
Age [<i>M</i> (<i>SD</i>)]	42.34 (10.98)	1-2 years	13
Located in United States	73 (74.5%)	3-5 years	20
Academic Fields		6-10 years	21
STEM	37	11-15 years	25
Helping Professions	32	16-20 years	12
Liberal Arts	34	21+ years	7
Educational Background		Autism/UD Experience	
Doctorate Degree	60	Prior autism training	40
Master's Degree	30	Prior UD training	35
Current Graduate Student	9	Has autistic family member	21

Improvements with training

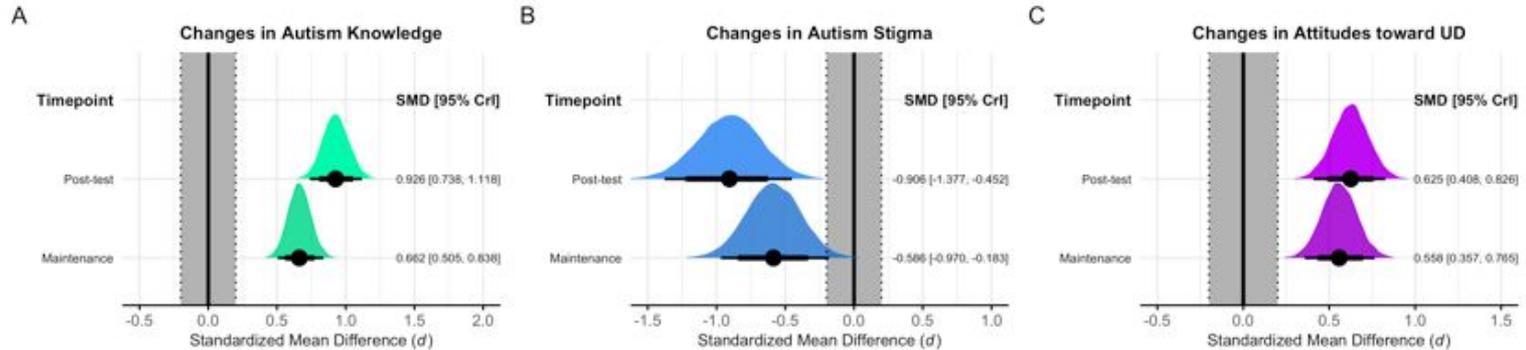


Figure 1. Changes in (A) autism knowledge, (B) stigma, and (C) attitudes toward UD at post-test and maintenance. Distributions represent the full posterior densities of change in each outcome (compared to pre-test), in pre-test standard deviation units (i.e., the standardized mean difference). The point, thick interval, and thin interval represent the posterior median, 80% highest-density credible interval (CrI), and 95% CrI for each distribution, respectively. Gray rectangles denote the region of practical equivalence (ROPE, i.e., interval null region), [-0.2, 0.2].

Take home points

- Structural barriers oppress neurodivergent people;
- Proponents of the neurodiversity movement advocate for supports but oppose normalization;
- Social connections help protect the mental health of neurodivergent people;
- Neurodivergent-led care and anti-stigma initiatives are needed but must be developed mindfully.

Thank you!!!

Allison Jordan
Amy Hurst
Annemarie Donachie
Ariana Riccio
Ashley J Harrison
Barbara Bookman
Ben Cheriyan
Beth Rosenberg
Billy Pinkava
Catherine Messina
Chinnu Cheriyan
Christopher Constantino
Christopher Cruz-Cullari
Chris Frka
Cristina Ulerio
Danielle DeNigris

Danielle Lopez
Danny Lopez
David Caudell
Denise Davidson
Eileen Parathyas
Eilidh Cage
Ellen Mullan-Jayes
Ellie Grossman
Emine Gurbuz
Eric Endlich
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Heather Brown
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Teddi Beekman
Zachary Williams
Zoilo Mercedes

