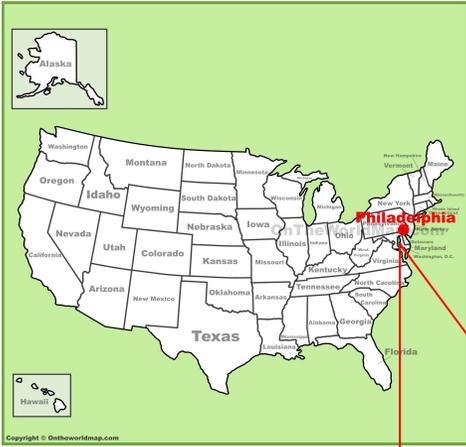


Emotional health in autistic adults: Research updates toward building better supports

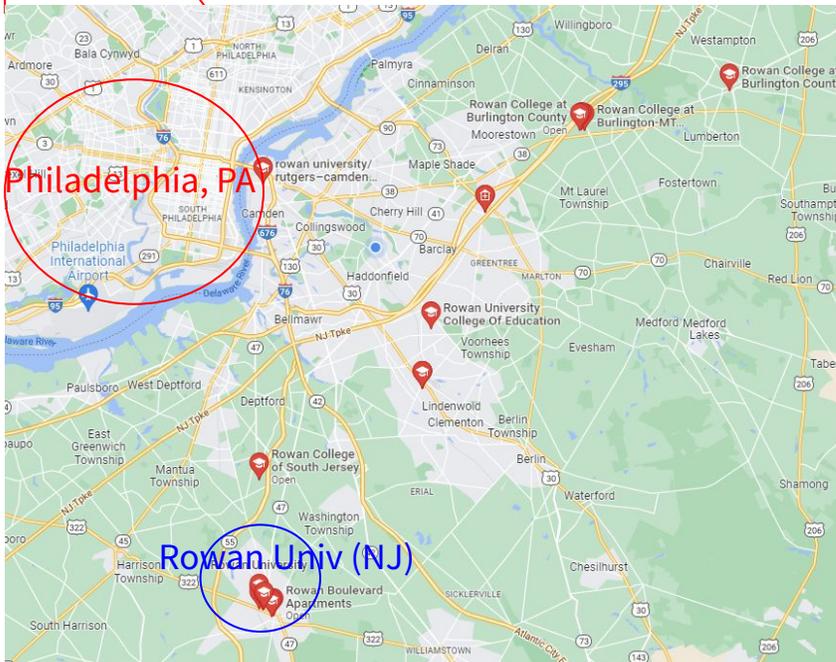
Katherine Gotham, Ph.D.
Department of Psychology, Rowan University
Glassboro, New Jersey, USA

SPARK Webinar
November 15, 2022





Research Program:
Identifying pathways to depressed mood in autism
to inform targeted treatment development



Overview of this presentation

Background on depression in autism:

- Prevalence & Impact
- Presentation & Assessment

Causes & Contributors

- Research updates from our lab

Treatment overview

Putting this all together: Next steps



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Depression is common in autism

- Autistic community ~4x more likely to experience depression (Hudson et al., 2019 meta-analysis)

Higher lifetime depression rates among autistic participants associated with:

- Increasing age (40.2% adult samples vs 7.7% in < 18 years old)
- Average to above average IQ (52.8% vs 12.2% when mean IQ is below average)
- Structured interviews to assess dep (28.5% vs 6.7% for other assessment methods)
- Self-report (48.6% vs 14.4% via caregiver report)

Impact of depression in context of autism

- Depression causes (or adds to) impairments in many areas:
 - Social skills, motivated social engagement
 - Adaptive behavior (daily living skills, communication)
 - Quality of Life, independence
 - Challenging behaviors and coping skills
- Depression in Aut also associated with systemic burden and other areas of risk:
 - greater use of service and meds
 - increased burden on caregivers
 - Suicidality
 - Heightened physical (e.g., gastrointestinal problems, seizures), emotional (e.g., anxiety), and behavioral (e.g., aggression, inattention) comorbidities
- Implications for autism interventions



The community is calling for this to be addressed...

- Mental health is commonly listed by autistic adult samples or groups as among their top research and clinical priorities

(HRSA-funded AASET working group, 2018 conference; Gotham, Marvin, Taylor et al., 2014)



“Traditional” features of depression seem to be common in autistic people...

- Sadness, crying
- Loss of interest and pleasure in activities
- Social withdrawal, general lack of motivation
- Sleeping and eating problems
- Decreased self-care
- Negative cognitions (failure, hopelessness, self-criticism)
- Thoughts about death

Some depressive symptoms may be more specific to autism...

- Changes in restricted interests
 - Markedly greater or lesser intensity
 - Change to morbid focus
- Increase in repetitive or ritualistic behaviors
- Irritability
- Increased aggression and/or self-injury
- Regressions or decline in self-care

**Is there an
autism-specific
presentation
of depression?
(1 of 2)**

**Overall,
presentation of
depression in autism
looks more similar
than different**

Is there an autism-specific presentation of depression? (2 of 2)

- Qualitative analyses of depressive experience in autistic adults
 - N=21 aut+dep participants
 - Structured Clinical Interview for DSM Disorders (SCID-5)
- Prototypical:
 - Loss of motivation; withdrawal from life (86%)
 - Suicidal ideation (86%)
 - Rumination, perseverative thinking (52%)

- Atypical:

- Unconventional metaphors
- Significantly increased interests

- Risk Factors

- Transition to adulthood
- Social difficulties
- Self-identity/acceptance of ASD

ences



Gloria Han, Ph.D. (Yale Univ)



Jessica Schwartzman, Ph.D.
(Vanderbilt Univ Med Ctr)

Validating a common depression symptom scale in autistic adults



- Beck Depression Inventory–II (BDI-II) in ~n=900 SPARK participants (aut) and ~n=900 community controls (non-aut):
 - Autistic and non-autistic adults answer questions in comparable ways, allowing for valid score comparisons
- Autism-specific normative scores and depression screening cutoff developed for clinical and research use
- Free online score calculator at https://asdmeasures.shinyapps.io/bdi_score



Zack Williams, Vanderbilt University

Sample Score Report

BDI-II Individual Score Report (Autism Calibration)

Patient Name/ID: Ann E. Donya Date: 08/21/2020

Summary Scores

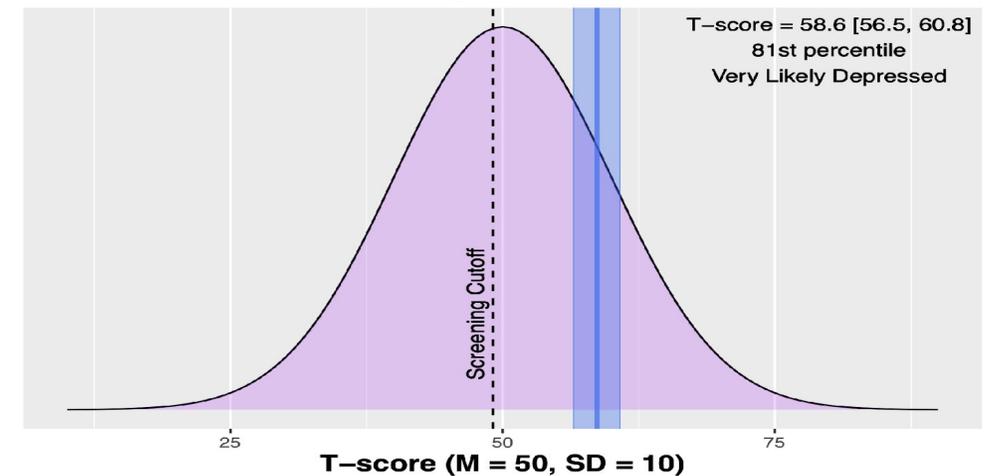
Screening Category: Very Likely Depressed

Suicidality: Active Suicidal Ideation Endorsed! Clinical risk assessment strongly advised.

Score Reliability: 0.99 (Adequate for score interpretation)

	Score	SE	95% CI Lower	95% CI Upper	Percentile
Z-score	0.8647	0.1097	0.6496	1.08	81
T-score	58.65	1.097	56.5	60.8	81

T–score Relative to Population of Adults with ASD



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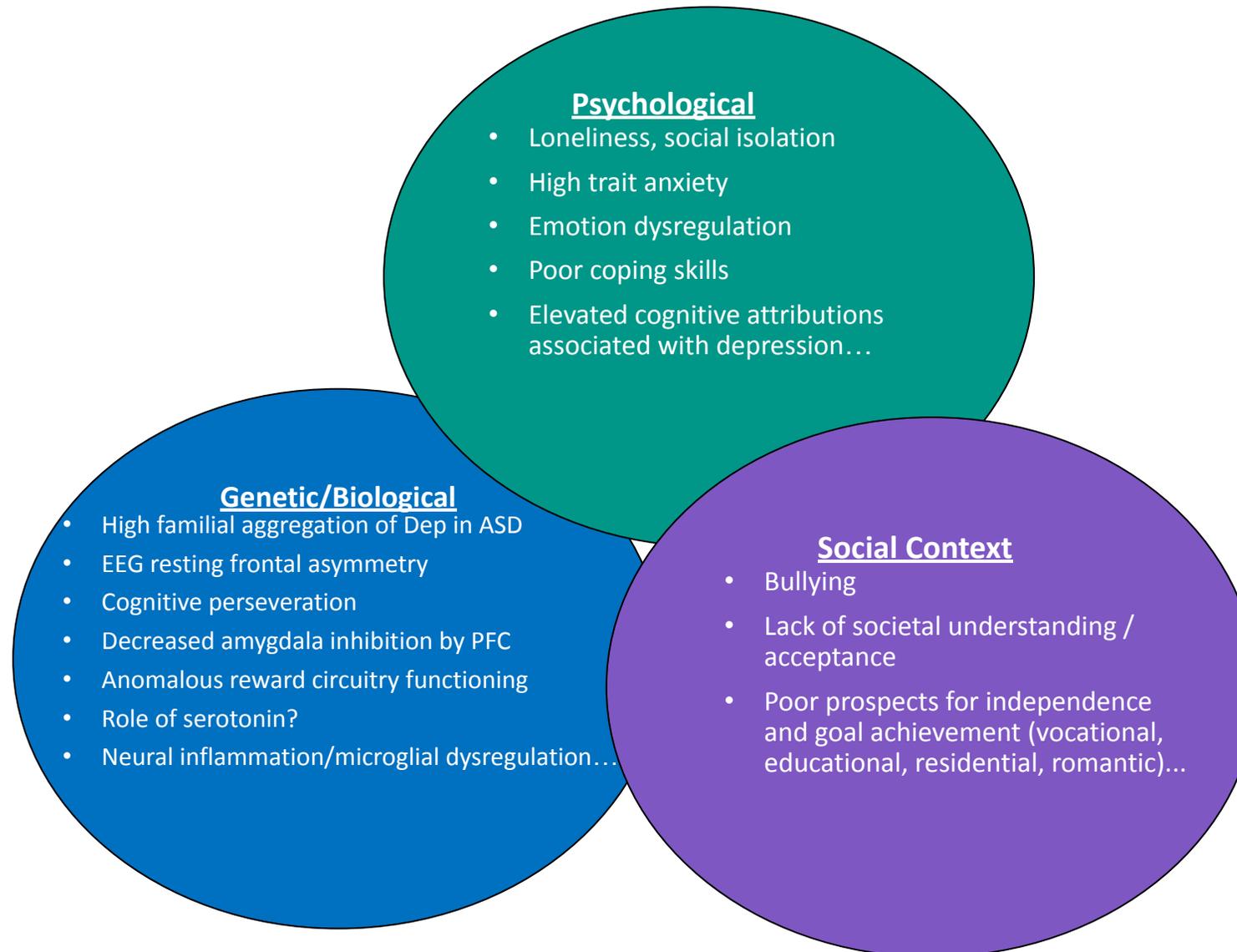
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Common pathways between Depression and Autism?



Bauminger & Kasari, 2000; Cacioppo et al., 2006; White & Roberson-Nay, 2009

²Gotham, Unruh, & Lord, 2014; Gotham, Bishop, Brunwasser, & Lord, 2014

³Kim et al., 2000

⁴Mazefsky et al., 2013

¹Shtayermman, 2007

²Gotham, Marvin, Taylor, et al., in press

³Henninger & Taylor, 2013

¹Bolton, Pickles, Murphy, & Rutter, 1998;

DeLong, 2004; Mazefsky et al., 2010

²Frick, Williams, & Pittenger, 2013

³Burnette et al., 2011

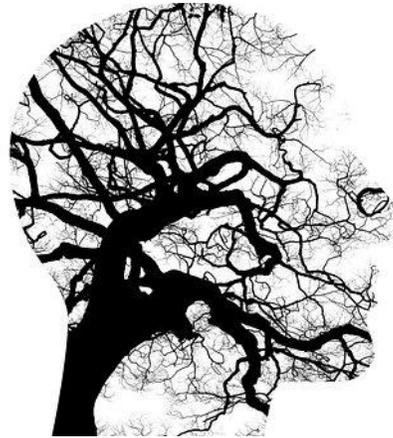
⁴Schipul, Keller, & Just, 2011; Siegle,

Steinhauer, Thase, Stenger, & Carter, 2002

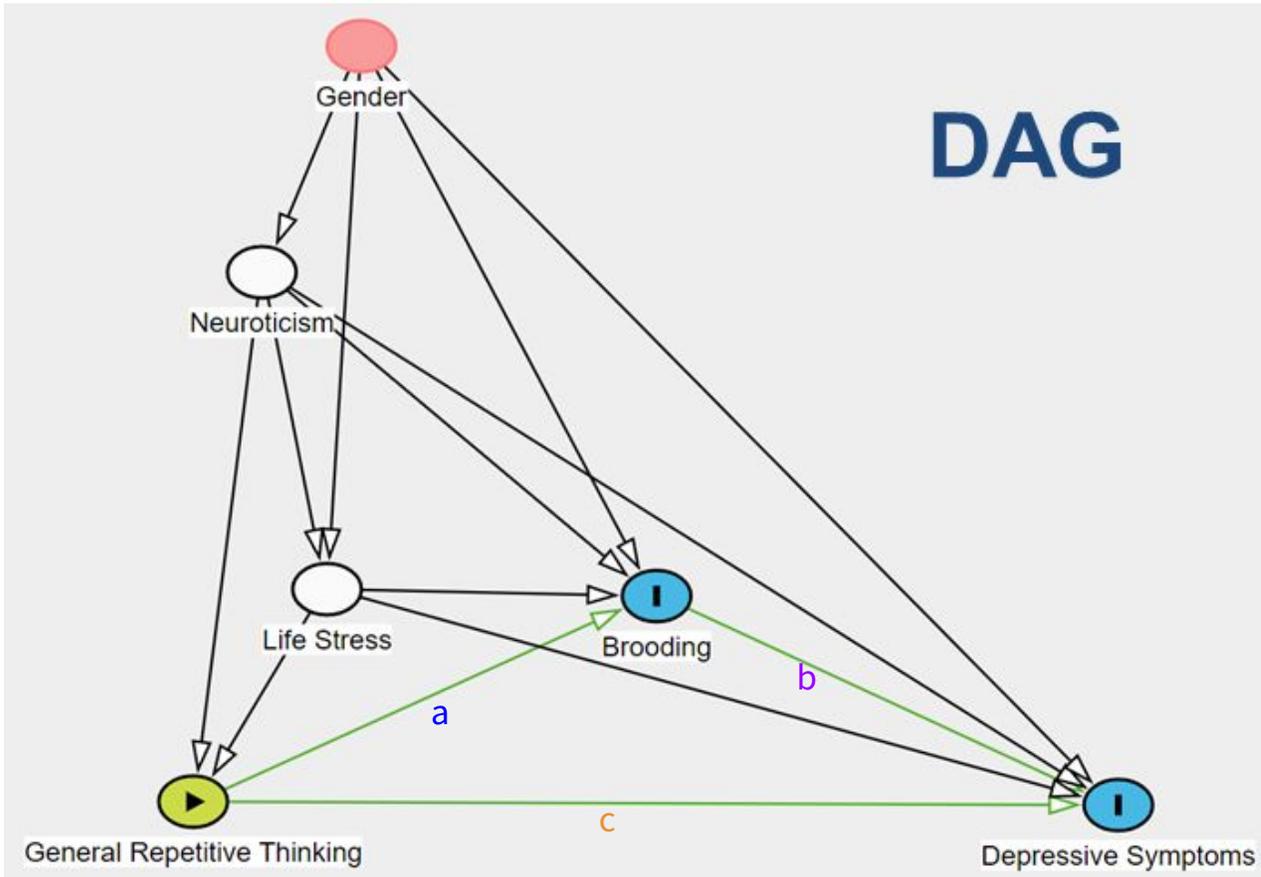
⁵Dichter, Damiano, & Allen, 2012

Looking for treatment targets: *Repetitive Thinking*

- Repetitive negative thinking (rumination) predicts or maintains depression, anxiety, suicidality, and other negative health outcomes in general population (Nolen-Hoeksema, 1991, 2000; Thomsen et al., 2004; Watkins, 2008; Miranda & Nolen-Hoeksema, 2007)
- Restricted, repetitive *behavior* (RRB) is a core symptom domain of ASD but repetitive *thinking* understudied in autism



Is RepT associated with depression? Yes and No.



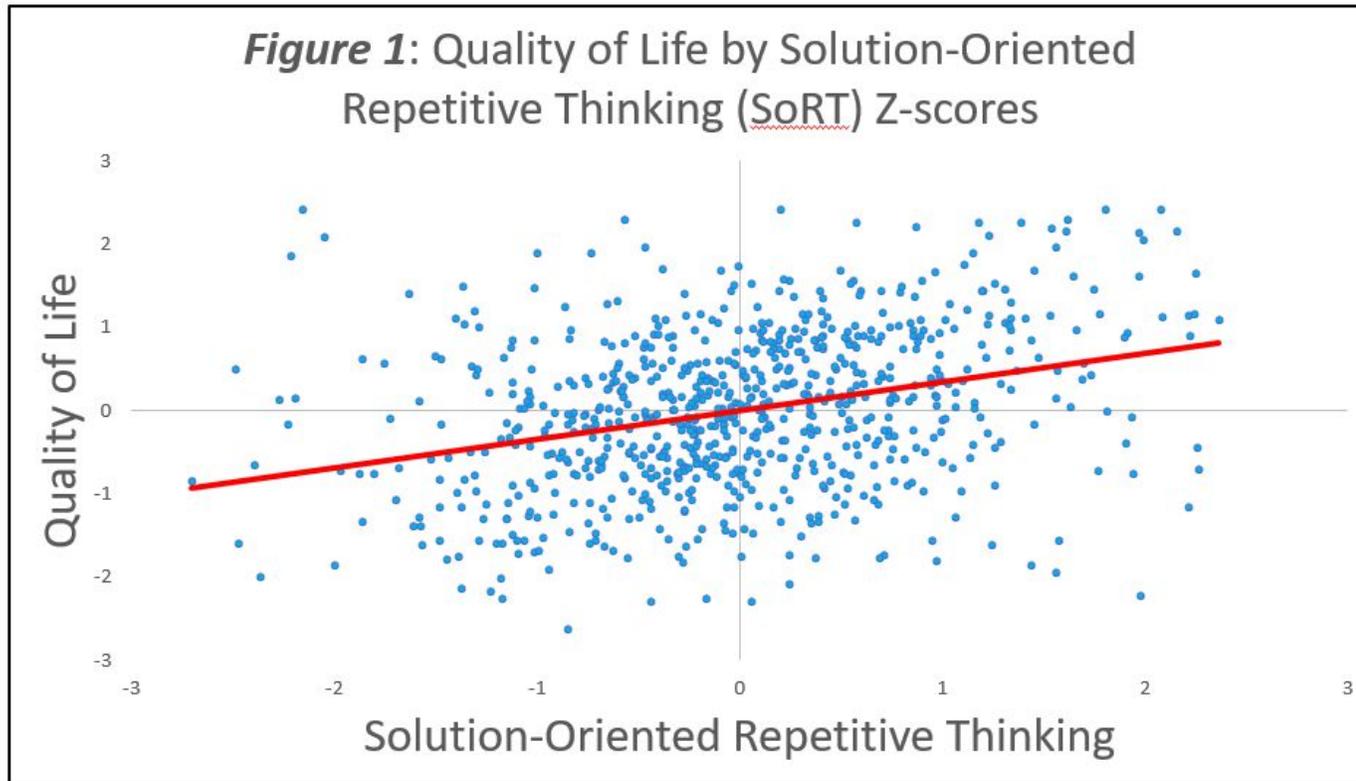
- Same SPARK sample (N=762, aged 18-45)
- In SEM, controlling for neuroticism & current life stress:
 - mediated path significant
 - direct (unmediated path) n.s.

That means,

- There was a positive indirect effect of RepT on dep sx through Brooding ($ab=0.11$, 95% CI [0.01, 0.21]).
 - General RepT pos assoc with Brooding ($a=0.18$, 95% CI [0.11, 0.26])
 - ...and Brooding pos assoc with BDI-II scores ($b=0.62$, 95% CI [0.14, 1.09]).
 - But there was a (slight) *negative* direct effect of general RepT on dep sx! ($c' = -0.09$, 95% CI [-0.17, -0.01])

That is, to the extent that general repetitive thinking did not lead to brooding, it had a protective effect.

...and certain forms of positive RepT indeed seem adaptive



In same SPARK adult sample, **better quality of life** was associated with:

- **Solution-oriented repetitive thinking**, $\beta = 0.28$, $t(731) = 7.457$, $p < 0.001$
- **Savoring**, $\beta = 0.07$, $t(731) = 4.797$, $p < 0.001$
- **Engaging in strong interests socially**, $\beta = .2$, $t(731) = 2.963$, $p < 0.01$



Rowan undergraduates Chris Pellegrino and Trey Scull

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Treatment

Common depression treatments hold promise for adapting to the autistic community

- **Cognitive Behavioral Therapy (CBT)**

- Highly effective in general population when delivered well
- Kerns et al., 2016: Adaptations for using CBT for depression in autism
- Challenges in Aut: maintaining/generalizing; not applicable to minimally verbal people

- **Behavioral Activation (BA)**

- Particularly helpful in those with low motivation or social withdrawal, or adults with minimally structured days

- **Mindfulness-Based Therapy**

- Relies on less insight, more observation/identification

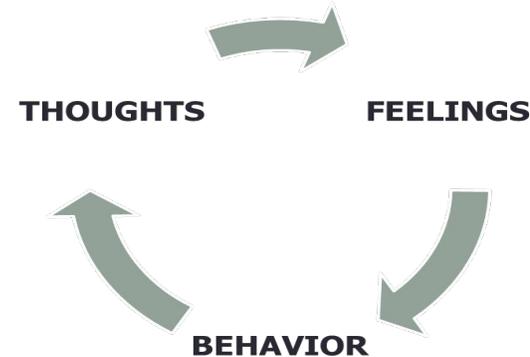
- **Acceptance and Commitment Therapy (ACT)**

- **Pharmacological**

Cognitive Behavioral Therapy

- Cognitive Behavioral Therapy (CBT) is based on the idea that how we feel and what we do are directly related to our thoughts (e.g., attributions, interpretations)

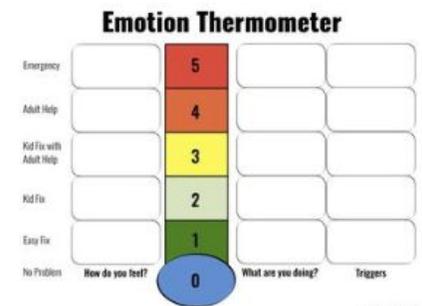
- Focuses on relationship between



- CBT successfully modified for anxiety in children/adolescents with ASD (Sukholodsky et al., 2013 meta-analysis; Chalfant et al., 2006; Sofronoff et al., 2005; Wood et al., 2009; White et al., 2013); heading this way for depression (Kern et al., 2016)
- One resource for finding CBT therapists in your area: <http://www.academyofct.org/> (then select “Find a Therapist”)

CBT modifications in Autism

- **Psychoeducation** to increase the individual's understanding of the depression diagnosis as a descriptor for maladaptive emotional symptoms (e.g., prolonged sadness), physical symptoms (e.g., fatigue, aberrant sleep patterns), and social consequences (e.g., social withdrawal and isolation), which helps to identify core skills for symptom improvement
- **Hands-on interactive** activities (e.g., role-playing, games)
- **Visual** analogue scales (e.g., fear thermometer)
- **Technology** (e.g., using phone applications to monitor daily mood)
- Parent and **family involvement**
- **Group therapy** to foster a community of social support and accountability, and to help the adolescent or young adult transition from family-centered support to peer support
 - (Kerns et al., 2016)
- Additional per Gloria Han, in prep: **Incorporate special interests** in therapy
 - To build engagement and rapport (“You teach me, I teach you”)
 - Strategies for content delivery (e.g., exposures, rewards, coping tools pertaining to interests)



What if one's own context is truly depressing?

- No magic answer
- Consider the framework of **Acceptance and Commitment Therapy (ACT)**

Instead of struggling against distress, clients are guided to accept that some negative feelings are **appropriate responses to certain situations**, and yet that this appropriate distress should **not prevent them from moving forward in their lives**.

From there, goal is to accept personal / situational hardships and commit to making necessary changes in behavior to move forward despite these hardships.

Focus on *prevention* of mood problems

- Healthy living, structured time
- Try to build social opportunity/engagement
- Incorporate special interests rather than suppressing

- Create an emotion regulation “toolbox”
- Support network: (tempered) vigilance in noticing behavioral changes





Physical

- **Get outside (if you can safely)**
 - Take walks, bike rides
 - Sit out to read a book or have a snack
- **Get moving every day**
 - Have WiFi? YouTube options (e.g., “Little Sports” channel for ~10 minute, simple animated workouts)
- **Got meds? Take them!**
- **Eat**
 - If possible: regularly, in moderation, with healthy choices
- **Sleep**

Sleep hygiene:

<https://www.helpguide.org/articles/sleep/getting-better-sleep.htm>

Social

- **Create opportunities**
 - Face-to-face
 - Schedule meaningful time with the people within your home (e.g., Family Game Night)
 - Socially distanced get-togethers
 - Online
 - Schedule FaceTime, Zoom, Google hangout calls
 - Start WhatsApp chats, Discord server with family and friends
 - Get to know new people through shared interests
 - Facebook, Tumblr, Twitter, Instagram, etc.
 - Hiki: autism friendship/dating site (www.hikiapp.com)
- **Keep your relationships healthy**
 - Say positive things
 - Truly listen
 - Disagree respectfully
 - Not working? Take a break.



Good article on recognizing and maintaining friendship:
<https://www.helpguide.org/articles/relationships-communication/making-good-friends.htm>

Mastery

- **Develop skills**
 - Cook a new dish, practice a new instrument, learn about interests
 - Can lead to feeling more creative
- **Accomplish things**
 - Check off on a to-do list
 - Can improve how we feel about ourselves



Fun

- **Enjoy for the sake of enjoying**
 - What brings you pleasure?
 - Hobbies, games, TV, movies, music
- **Create a list of options**
 - Keep track and add as you think of more
 - Choose what sounds most fun for that moment



Service

- **Contribute**
 - Thoughtful ways to give back to others
 - Help someone out or do something nice for someone
- **Small actions count!**
 - Donating money / saving a life is not the only way to help!
 - We can help family members or those we live with
 - Do laundry
 - Clean a room
 - Surprise someone with a note/card
 - Prepare a meal or snack

Digging a little deeper in these unusual times...

- Practice *tolerating uncertainty*
- Practice *flexibility*
- Practice *moderation*
 - Limit media consumption
 - Limit screentime (somewhat)
 - Balance mastery and fun
- Practice *gratitude*



Organize your experience the way you want it

- Make a schedule
- Redecorate, de-clutter
- Seek some solitude, sensory experiences

Terrific COVID-19 Toolkit by/for autistic adults:

<https://ausm.org/images/docs/PandemicGuideforASDAdults2020.pdf>

Ask directly for social support

- “I am feeling lonely right now, I would really appreciate hearing from you.”
- Encourage people to talk about themselves.

“Like many of us, I am being productive when I can, and —perhaps most importantly— **I am being kind to myself** when I cannot.”

Jac Den Houting, “Stepping Out of Isolation: Autistic People and COVID-19”

https://www.liebertpub.com/doi/10.1089/aut.2020.29012.jdh?utm_source=Adestra&utm_medium=email&utm_term=&utm_content=Read+Now&utm_campaign=AUT+FP+Apr+27+2020+covid&

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Prepare ahead of time, then use your “menu”

RELAXATION

- Progressive muscle
- Visualization/imaginative
- Breathing exercises
- Repetitive action or sensory input (at appropriate time)
- Quiet activity (model building, drawing)
- Music – listening/playing
- Reading

SOCIAL TOOLS

- Spend time with family member or friend
- Be with a pet
- Ask for help (to clarify what just happened, to give reminders of calming strategies, to help employ thinking tools)

PHYSICAL ACTIVITY

- Exercise – e.g., trampoline
- Sport
- Creative/destructive
- Swing

THINKING TOOLS

- Put event in perspective
- Promote flexible thinking (e.g., “It might have been an accident. I should check before I get angry”)
- Social story
- What would you like to do? Desired outcome? How to get there?

Mood in the minimally verbal population

- Rather than verbal report, rely on behavioral change (particularly in areas of self-injury, aggression, irritability, tearfulness)
- Focus first on behavioral activation strategies and increasing self-help skills
- Increase social exposure
- Try alternative therapies like art, music, etc.

- We are currently piloting a nonverbal eyetracking task to index depressive symptoms in autistic adults with limited or no spoken language.

Contact seahl@rowan.edu for more info!



Robyn Himmelstein

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Depression in autism (Summary)

- Prevalent – rates 4x greater than general population (Hudson et al., 2019)
- Impactful – assoc with poorer phys/ment health, qual of life, caregiver burden, suicidality
- Research prioritized by community (Benevides et al., 2020)



Depression in autism (Summary, cont.)

- Assessment and diagnosis is challenging
- Evidence for effective treatment is limited, but adapted psychotherapies show some promise.
- We hope that focus on potential causal pathways (e.g., repetitive thinking, social motivation) may lead to improved interventions

Next steps

- Better measures → better research
 - BDI-II seems to work in autistic adults! (Williams, Everaert, & Gotham, 2020)
 - Cassidy/Rodgers group (2021): *Autistic Depression Assessment Tool - Adult (ADAT-A)*
 - Our lab is currently validating 2 new self-report instruments in aut adults: 1 for depression, 1 for rep thinking
- “No man left behind” – focus on vulnerable subgroups
 - Gender and sexuality minorities, those with limited language and/or intellectual disability, child/adolescent populations
- “No stone left unturned” – focus on diverse potential causal contributors
 - Camouflaging, burnout, employment, romantic & other life goal fulfillment, nutrition, sleep, trauma
- “Thinking outside the box” – we need more than just clinicians/researchers working on this
 - Community involvement
 - Multidisciplinary teams, novel disciplines



“Long game” & “Fast track”: We need both now

- We need careful, thoughtful research for long-term solutions
 - That is usually slow and meticulous
- We need wide-scale social change toward acceptance and respect



AND



- We need creative, nimble “bandaids” in the meantime
 - e.g., continuing education packages on autism for clinicians who already know depression tx
 - building awareness to keep this on the radar for families and providers

With grateful acknowledgment

SEAHLab team:

- Emmanuel Avila
- Robyn Himelstein
- Erin McKenney
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- Jared Richards
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- Trey Scull
- Elisha Sotrah

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- Kristen Gillespie-Lynch, Bella Kofner (CUNY-Staten Island)
- Erin Kang, Rachel McDonald (Montclair State)
- Matt Lerner, Talena Day (Stony Brook)
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Adult participants and their families

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- Jessica Schwartzman (Vanderbilt Univ Med Ctr)
- Zack Williams (Vanderbilt Univ)



- SPARK participants!!
- Brianna Vernoia
- Casey White
- Mahfuza Sabiha
- Malak Enayetallah
- Tempus Dynamics

Thank you for listening!

Questions/comments?

gotham@rowan.edu
seahl@rowan.edu

Please contact us if you are interested in participating in person!

We are currently recruiting for:

Roundabout Minds Project

- Verbally fluent adults
- aged 18-45
- with autism and/or current depression
- no history of bipolar/schizophrenia

Tracking the Blues in Minimally Verbal Adults

- Autistic adults with limited or no spoken language
- aged 18-45

Our lab is in Glassboro, NJ

- 20 min south of Philadelphia
- 2 hours south of New York City
- 1 h 45 min north of Baltimore



SEAHL
Social, Emotional,
& Affective Health Lab

Contact: seahl@rowan.edu



Seeking Research Participants: Autistic Adults who are Minimally Verbal or Nonverbal



We want to learn more about emotional health and markers of depressed mood in people who do not use much verbal speech.

We are inviting adults to participate in a research study. Participants will receive...



Seeking Research Participants: Adults on the Autism Spectrum



We are inviting adults to participate in a study about thinking styles, feelings, and health. This study includes interviews, questionnaires, and looking at pictures on a computer screen. You might be a good fit for this study if you:

- Are 18-45 years of age
- Have an autism spectrum diagnosis (ASD, autism, Asperger's syndrome, Pervasive Developmental Disorder)

Participation is voluntary. This study will take about 5-7 hours of your time. For full participation, you will receive \$100, a T-shirt, and selected assessment results.

Contact:
SE AHL@rowan.edu
(856)-240-0930

This study has been approved by the Rowan University Institutional Review Board (Pro2019000852)



For more information, contact Claudia Cucchiara of the Roundabout Minds Project