

Healthy Relationships on the Autism Spectrum (HEARTS): A healthy relationships class for autistic people co-taught with autistic teachers

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Funding from NIMH: K18MH122791 & OAR 2019

Sensitive topic

- Trigger warning: We talk about abuse and violence in this presentation

ASAN
AUTISTIC SELF-ADVOCACY NETWORK

NOTHING ABOUT US WITHOUT US
ABOUT RESOURCES POLICY PROJECTS GET INVOLVED DONATE

Identity-First Language

ASAN notes (also from an originally published article in their blog *Autistic Ways* under the title *The Significance of Pronouns: Person-First Language: Why It Matters*):

At the Autistic Services Indemnity's first meeting last Wednesday, much to do was made about someone's disagreement — "not individual" versus "individual with ASD" and of course the dreaded "person with autism" or "person who has autism" versus "autistic person." These issues of semantics are far less innocuous and apologetic...

Words and language are powerful tools by which an individual can express ideas, whether abstract, concrete, or concrete. As a writer and editor, I have frantically done language and the meanings we attach to words very much impact, influence, deflect, and change the attitudes that we have toward the subjects of discussion. That is why people are easily misled or spun by word choice. Changing a phrase — even if it holds the same literal meaning — alters the subtle connotations and nuances of the speech, and connotations are different meaning and sense than the original phrasing.

In the autism community, words such as *autism* and their other related meanings such as "autistic," "autistic person," or "autistic individual" because we understand autism as an inherent part of an individual's identity — the same way you refer to "Shakespeare," "the Democrats," "Indie as a genre," "Indie as a style," "Chicago as a city," "Chinese," "yellow," "cubicle," or "Friday." On the other hand, many prominent autistic people and professionals who work with autistic people prefer terminology such as "person with autism," "people with autism," "an individual with ASD" because they do not consider autism to be part of an individual's identity and do not want their children to be identified as "autistic." They want "person first language," that puts "person" before any identifier such as "autism," in order to emphasize the humanity of their children.

Resources:

Botha, M., Hanlon, J., & Williams, G. L. (2021). Does Language Matter? Identity-First Versus Person-First Language Use in Autism Research: A Response to Vivanti. *Journal of Autism and Developmental Disorders*, 1-9.

Dunn, D. S., & Andrews, E. E. (2015). Person-first and identity-first language: Developing psychologists' cultural competence using disability language. *American Psychologist*, 70(3), 255-264.

Bullying

46-96% of autistic youth (Morton, 2021)

Dissatisfied with current number of friendships

60% of autistic people ages 18-24 years old (as compared to 18% of non-autistic people) (Finke et al., 2019)



NLTS2 data from 2009
n=600 (ASD)

Autistic youth vs. youth with ID
Grannan et al., 2013

- 1 Never see friends: 39% vs. 20%
- 2 Never get called by friends: 47% vs. 17%
- 3 Never be invited to activities: 48% vs. 37%
- 4 Socially isolated: 28% vs. 9%

Consequences of difficulties with social relationships



40% of autistic adults do not experience reciprocal friendships (Kobayashi and Murata, 1998; Howlin et al., 2000)

Most autistic people experience sexual attraction



- The idea that most autistic people are asexual has been debunked (Kelaheer, 2015)
 - 5% of autistic men and 15% of women feel no sexual attraction (compared to 1-2% of controls) (Dewinter, De Graf & Begeer, 2017)
- The idea that many autistic people feel same-gender attraction is supported
 - 18% of autistic men and 44% of autistic women feel some same-gender attraction (Dewinter, De Graf & Begeer, 2017)

- UCLA Peers
- SDARI
- Skills Streaming
- Social Stories
- MASSI
- Sensory Enrichment Therapy
- Sense Theater
- Transitioning Together
- SOSTA-FRA
- Reciprocal Imitation Training
- KONTAKT
- The Access Program
- Alvin model of free improvisation
- Superpower Glass Intervention
- Social Tools and Rules for Teens
- Mind Reading (computer software)

Social skills interventions (N=16)

What are social skills?

Social skills facilitate interaction and communication with others and may be verbal nor nonverbal.

Examples of social skills include:

- Initiate a conversation
- Take turns in conversation
- Make eye contact
- Ask open-ended questions
- Express interest in the other person
- Do not interrupt during a conversation
- Respect personal space bubble

What are healthy relationship skills?

Healthy relationship skills encompass the knowledge, competencies and abilities to initiate, maintain, and—if necessary—end friendships and intimate partnerships.

Examples of healthy relationship skills include:

- Knowledge about what counts as abuse
- Recognizing equitable and respectful behavior
- Communicating and respecting boundaries, including sexual consent
- Ability to communicate affection and attraction in a mutually-acceptable way
- Resolving conflict and problem-solving
- Having difficult conversations
- Knowledge about how to end relationships

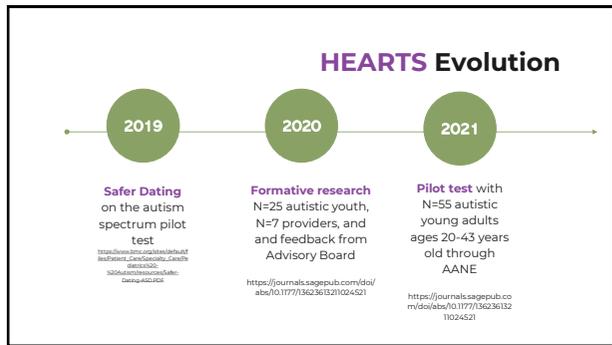
- UCLA PEER-DM
- Supporting Teens with Autism in Relationships (STAR)
- Tackling Teenage Training (TTT)

Healthy relationships interventions (N=3)



Advisory Board

- M. Chiang
- Amelia Sanchez
- Reid Caplan (ASAN)
- Peter Wharmby
- Mariah Person



Original Article

Using formative research to develop HEARTS: A curriculum-based healthy relationships promoting intervention for individuals on the autism spectrum

Emily F Rothman and Laura Graham Holmes

Abstract
 Curricula that teach relationship skills to autistic individuals are needed. The purpose of this formative research study was to describe the views of autistic youth about healthy and unhealthy friendships and dating relationships, in order to uncover what types of skills they felt would be useful to learn in a workshop-style intervention in order to have healthier peer relationships. The research was shaped by input from a five-person Advisory Board comprising autistic people. Twenty-five autistic individuals aged 16-22 years old were interviewed. The interviews were analyzed using an inductive content-based analysis approach. Interview participants described finding it challenging to remain motivated to make and maintain friendships, and that they would benefit from education about overcoming anxiety rooted in bad prior experiences that stop them from making new friends, learning when it was safe to take emotional risks, how they could cultivate reciprocity in relationships, and how to identify, communicate, and respect sexual and emotional boundaries. They also voiced a preference for mixed-gender interventions team taught by one neurotypical and one autistic facilitator. The experiences, opinions and preferences of the 25 autistic youth who were interviewed will inform the content of the forthcoming Healthy Relationships on the Autism Spectrum relationship skills intervention.

Logistics

Class composition

- Mixed neurotypical and autistic facilitators
- On Zoom

- Mixed gender audiences
- Think broadly about age

HEARTS Teacher qualifications

- (a) prior experience using dating apps;
- (b) comfort discussing contemporary dating and sexual relationship topics including polyamory, kink, same-sex sexuality, pornography, and asexuality
- (c) a commitment to anti-racist, anti-ableist, and gender and sexual minority supporting practice
- (d) firsthand experience making friends, ending friendships, falling in love, and ending a serious intimate partnership;
- (e) prior experience facilitating group discussions online and familiarity with Zoom; and
- (f) capacity to attend HEARTS-related supervision meetings weekly.

Deficit model vs. neurodiversity perspective

22-year-old non-binary participant
 Theme 2: Overcoming anxiety rooted in bad prior experiences

“I’ve grown up being taught, often pretty explicitly, that the way I interact with people is wrong and there is something wrong with me, and so I avoid interacting with others because I’ve internalized that so thoroughly... Like, our ‘social anxiety’ is not always an unfounded fear.”

Sex positive



Session	Theme	Topics
1	Defining healthy relationships	-Healthy vs. unhealthy relationships -Warning signs of unhealthy relationships
2	Launching new relationships	-Developing curiosity in other people -Active listening
3	Neurohealth for relationships	-Fight, flight or freeze responses -Why eating, sleeping, exercising are important
4	Meeting new people	-How to meet people -Perspective-taking -Handling jealousy
5	Boundaries	-Understanding boundaries -Renegotiating boundaries -Apologizing and accepting apologies
6	Ending relationships	-Domestic violence and sexual assault hotlines -Signs a relationship should end -How to end relationships

Healthy relationships...

- Make you happy
- Feel good to both people
- Are steady
- You can count on the other person
- Trust
- Respect
- Interdependence
- Cooperation
- Compromise
- Bring out the best in you
- Sexual attraction (if sexual relationship)
- Room to grow and change
- Lots of laughs or joy

Warning signs of an unhealthy relationship

- Repeatedly unkind
- Tries to control you
- Is violent, jealous, possessive
- Has a scary temper
- The person uses drugs or alcohol in an unhealthy way
- Gets too serious too fast
- You'd rather not hang out with them
- They cheat on you or you cheat on them, or otherwise violate your boundaries one too many times
- They make you feel stupid
- They make you do things that you don't want to do

[SafeLink](#) domestic violence hotline: 1-877-785-2020

What happens when brains do not get what they need?

- Hungry
- Tired
- Frightened
- Stressed



Then what happens?

5 More brain problems

- Cognitive failures (mistakes)
- Less rational thinking
- Burnout
- Executive function
- Motivation

6

Relationship problems

- Mistake in judgments
- Assume the worst
- Paranoid
- Stuck-thinking
- Giving up
- All or nothing thinking
- Irritable
- Aggressive
- Withdraw
- Take rejection personally
- Less attuned to consent
- Less attuned to friend's desires

How to reconnect with an old friend

- Step 1: A simple text**
 - Hey, how have you been?
 - I haven't talked to you in forever!
 - You just bring about you when I watched *The Office* the other day!
- Step 2: Expand the conversation**
 - Ask deeper questions
 - Ask about their current situation
- Step 3: Share a few key updates**
 - Stay positive!
 - New job or home?
 - New author or hobby or passion or food?
- Step 4: Bring up good memories**
 - I still think about the fun we had with that *Office* marathon!
 - I have never met anyone else who has that special way of looking that you have.
- Step 5: Make a plan for next time**
 - Get together: when, where, how?
 - OK! I will too specific the first time you next

"How can we make this work?"

- 1) Say your problem.
- 2) Acknowledge their side.
- 3) Ask how to make it work.

Example:

- 1: I've been feeling frustrated about doing most of the chores at home.
- 2: I understand that you are busy, but I'd like to share the chores.
- 3: How can we make this work?



Alison is tired of contacting her friend Caitlin and never hearing back from her. Caitlin almost never replies to her. Alison used to consider Caitlin her best friend, but now she doesn't want to think.

Should she tell Caitlin the friendship is over?

Move a Relationship Forward

- 1 Meet or get in Touch**
 - The goal is to get someone's name and contact information
- 2 Chat**
 - The goal is to have a back-and-forth conversation where both people ask and answer a few questions.
- 3 Hang Out**
 - The goal is to spend time together either online or in person. Do an activity together. Take a walk, play a game, get a coffee, be part of the same event.

What if who I am as a person is...

- Cherishing my inflexibility—it's who I am
- Being authentic about (negative) viewpoints
- Refuse to back down when I know that I am right
- Not going to pretend to be interested if I am bored

Yes: it's your choice and your right

You can also experiment with softening your stance, if you want—what are the outcomes?

Research study (N=55)

- One-group pre/post test design
- All procedures approved by the IRB at Boston University
- Participants registered for HEARTS through the organization AANE
- Used valid and reliable survey measures
- Qualitative feedback on class

Special Issue: Community Development and Implementation



Healthy Relationships on the Autism Spectrum (HEARTS): A feasibility test of an online class co-designed and co-taught with autistic people

Emily F Rothman¹, Laura Graham Holmes², Reid Caplan¹, Melody Chiang¹, Brandy Haberer¹, Nick Gallop¹, Rabindra Kadel¹, Mariah Perron¹, Annelia Sanchez¹, Emily Quinn¹ and Peter Wharmby⁴

Abstract
 This study tested the feasibility and preliminary efficacy of a six-session online class on healthy relationships for autistic individuals ages 18–44 years old (N=55). The content of the Healthy Relationships on the Autism Spectrum class was informed by formative research with 25 autistic individuals, and developed collaboratively by ten non-autistic professionals and seven autistic self-advocates. Fifty-five autistic people participated in Healthy Relationships on the Autism Spectrum and completed pre- and post-surveys. The study found that it was feasible to deliver Healthy Relationships on the Autism Spectrum online. Pairing an autistic and non-autistic person to co-teach was well-received. Participants decreased hostile automatic thoughts ($p < 0.05$), involvement in dating abuse in intimate relationships ($p < 0.05$), right-or-wrong responses ($p < 0.05$), and rejection sensitivity ($p < 0.001$). Participants experienced improved flourishing ($p < 0.001$), coping with rejection and jealousy ($p < 0.001$), motivation to engage with others for socializing ($p < 0.05$), self-compassion ($p < 0.05$), and positive thinking ($p < 0.05$). Scores on a measure of interpersonal competence did not change, and loneliness did not decrease. The majority of participants reported high satisfaction with the class. Healthy Relationships on the Autism Spectrum is a promising healthy relationships prevention class that should be evaluated through a randomized controlled trial.

Participant satisfaction

participants scored the class as a **3** (on a scale from 1 to 10, with 1 representing the best)

- 27%** reported that the workshop improved their ability to meet new people
- 60%** reported improved their ability to have healthy relationships
- 60%** reported that the workshop taught them how to improve their relationships

HEARTS study participants (N=55)

- 20-43 years old
- 80% White, 7% Multiracial, 6% Black, 6% Asian
- 55% female, 31% male, 11% non-binary
- 6 had an intellectual disability
- 47% lived with parents
- 56% were employed
- 82% had diagnosis of anxiety
- 76% had diagnosis of depression
- 46% had ADD or ADHD
- 26% had PTSD

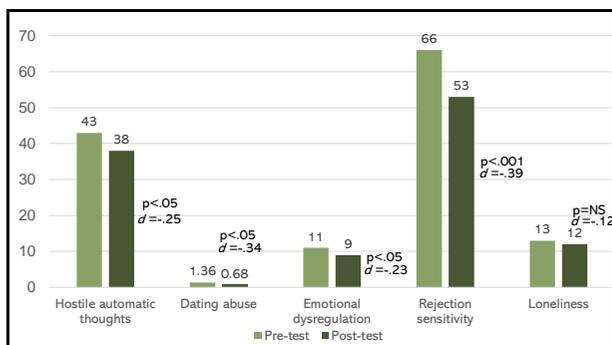
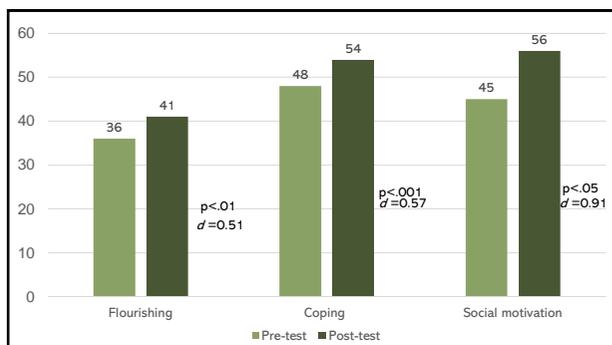
HEARTS outcomes

Increase

- Flourishing
- Coping
- Social motivation

Decrease

- Hostile automatic thoughts
- Dating abuse
- Emotional dysregulation
- Rejection sensitivity
- Loneliness



HEARTS feedback

"I was grateful that there was an autistic moderator"

"I liked that a person on the spectrum was...teaching the class. It's nice to have someone on the spectrum talk about their own experiences and how they handle certain situations."

Participant critique

- (1) there were too few sessions and too much material
- (2) some topics felt less relevant to some students, and they felt bored during those
- (3) frustrations with the way that some participants used the chat feature on Zoom

Laura's reflections

- (1) What it was like to work with the Advisory Board
- (2) What it was like to co-teach with an autistic teacher

Reid's reflections

- (1) What it was like to be on the Advisory Board and work with this research team
- (2) Thoughts about the HEARTS class

Next steps

1

Recruiting sites
for RCT

2

Securing funding

Next Steps

ORGANIZATION FOR
AUTISM RESEARCH
PROJECT



E-Learning training for
college sexual assault
counselors



Informed by
autistic students



Wide testing; you
are invited to
participate

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