



HHS Public Access

Author manuscript

Autism. Author manuscript; available in PMC 2023 January 01.

Published in final edited form as:

Autism. 2022 January ; 26(1): 160–168. doi:10.1177/13623613211024521.

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

Emily F. Rothman, Laura Graham Holmes

Boston University School of Public Health

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 ages 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 (HEARTS) relationship skills intervention.

Lay Abstract

What is already known about the topic?—All people can benefit from education about how to have healthy friendships and dating relationships. But specific interventions on relationship skills—like respecting boundaries, identifying warning signs of abuse, or talking about sexual preferences—are too rare, particularly for autistic individuals. The goal of this study was to collect formative data from autistic emerging adults to help create a new, six-session workshop for autistic young adults to support healthy peer relationships. Twenty-five autistic youth ages 16–22 years old were interviewed.

What this paper adds?—The participants described a need for more and better information about how to support lasting friendships, deal with their anxiety about relationships, and know when friendships or dating relationships were reciprocal and rewarding vs. unhealthy.

Correspondence concerning this article should be addressed to: Emily Rothman, Boston University School of Public Health, Department of Community Health Sciences, 801 Massachusetts Ave, Floor 4, Boston MA 02118. erothman@bu.edu.

We have no conflicts of interest to disclose.

Implications for practice, research, or policy.—The results reveal a need for a new and effective intervention that supports healthy relationship skills for autistic people.

Developing and maintaining healthy relationships with peers, as friends or intimate partners, can be challenging for anyone—and is often particularly challenging for autistic individuals. A recent meta-analysis found that as many as 44% of autistic people experience bullying victimization by peers (Maïano et al., 2015), and 28% engage in peer aggression as well as experiencing victimization (Chou et al., 2019). Compared with non-autistic adolescents, autistic adolescents have a 56% increased risk of being bullied (Lebrun-Harris et al., 2018). While bullying involving physical violence occurs more at younger ages (Maïano et al., 2015), more subtle forms of emotional abuse, such as peer shunning and relational bullying, become more common as autistic youth age into adolescence and young adulthood (Sreckovic et al., 2014). Sexual assault victimization is also too common among autistic individuals. A study that investigated sexual assault victimization among autistic college students on nine U.S. 4-year college campuses found that 8.2% of 158 autistic college students reported unwanted physical sexual contact within the preceding five years, while only 4.6% of those without a disability did (Brown et al., 2017). Unfortunately, few people—whether neurotypical or on the autism spectrum—are taught how to recognize, develop, and maintain healthy and mutually rewarding peer relationships in formalized classes.

Most autistic individuals have difficulty with social communication and as a result many have problems making and keeping friends (Lasgaard et al., 2010). Analysis of data from the National Longitudinal Transition Study-2 (NLTS2) found that autistic adults, as compared to those with other disabilities, were significantly more likely to never see friends, never get called by friends, never be invited to activities, and be socially isolated (Orsmond et al., 2013). A 2009 nationally representative survey of autistic young adults found that 25% had not had any contact with friends for at least a year, and that 33% did not participate in any community activities (Roux et al., 2015; U.S. Department of Health and Human Services, 2017). To address this problem, numerous social skills interventions have been developed and tested, in various countries and cultural settings, with a wide variety of age groups of autistic youth. These include, for example, the UCLA Peers program (Laugeson et al., 2012), the UC Davis ACCESS program (Oswald et al., 2018), the UC Santa Barbara Social Tools and Rules program (Vernon et al., 2018), and the Multimodal Anxiety and Social Skills Intervention (MASSI) (White et al., 2013). Many of these social skills interventions teach social pragmatics such as the importance of taking turns in conversation, showing interest in another person's comments in a conversation, making eye contact, regulating voice volume or tone, and not crowding a person physically during a conversation. Some also teach social skills such as perspective-taking, flexible thinking, problem solving, and self-regulation. However, few of these interventions focus exclusively on what might be considered relationship skills, including how to identify and respect interpersonal boundaries that can vary from individual to individual, or how to assess whether relationships are mutual, fulfilling, and supportive. For example, when it comes to dating partners, each person may have a different level of comfort with physical sexual intimacy like holding hands or kissing with tongue, and their boundary may change by the day or even by the hour based on how they are feeling. The skill of communicating with a partner about their physical sexual intimacy boundaries in the moment is important and too rarely taught.

Relationship social skills, such as communicating needs to a friend who consistently breaks plans or has otherwise caused hurt feelings, or assessing if a relationship is mutual, are important for non-sexual friendships, as well.

The present study responds to the recent call for “additional research to develop and rigorously test interventions for adults with ASD that target the many behavioral components of social functioning” (Pallathra et al., 2019). As a first step in the development of a new curriculum, the present study was undertaken to collect formative data. There is no one correct way to approach formative research; it is typically an iterative, or cyclic, process of exploring and confirming what is known about a problem, and developing a sense of what will be the most effective intervention strategies (Leviton et al., 1999). We undertook this qualitative research as the first step in a multi-step intervention development process for a new healthy relationships promotion intervention called HEARTS (Healthy Relationships on the Spectrum). Thus, the specific aim of the present study was to elicit the views of emerging adult autistic individuals about healthy and unhealthy friendships and dating relationships, with a focus on what topics or skills would be helpful to teach in a healthy relationships intervention.

Methods

All procedures were approved by the Institutional Review Board (IRB) at the Boston University School of Public Health. Autistic community members were involved in the design of the research study, and provided input on youth eligibility criteria, interview questions, and data interpretation during two research-focused online meetings in 2020. The project Advisory Board comprised five autistic individuals who were recruited before the research project began. They were recruited using a combination of internet advertising and direct invitations, and engaged in an interview process before selection. The Advisory Board members ranged in age from 16 to 34 years old, four were U.S. residents and one was a U.K resident, two identify as White and three identify as Asian, Black, and Multiracial, respectively. One was a representative of the Autistic Self-Advocacy Network (ASAN). Advisory Board members were paid approximately \$100 per hour to participate in approximately five hours of meetings over the course of this research project and subsequent intervention development sessions.

Participants

We recruited a convenience sample of autistic youth via social media advertising and from two databases (one belonging to each co-author) of prior research participants who consented to be re-contacted for future studies. Eligible youth were those that: (1) were 16–22 years old; (2) living in the U.S.; (3) English-speakers; (4) had a diagnosis of autism from a health professional, which the research team verified by reviewing a copy of their diagnostic evaluation report, Individual Education Plan (IEP), or other letter from a health care professional; (5) reported that they had one or more close friends according to the definition provided (see below); and (6) were capable of participating in an interview independently, without parent or caretaker assistance. The age range of 16–22 years old was selected because the goal was to collect information from emerging adults who may

have had an interest in dating and experience with close friendships, but a narrow age range was selected in order to keep the sample within the same maturational/developmental age group. For the purpose of this study, a “close friend” was defined as a person who was within two years of their age, not related to them, not employed to work with them, and someone that they would spend time with outside of school or work for socializing purposes if the COVID-19 pandemic was not limiting activities. Friends that someone knew only from online settings and encounters did count as friends.

Capacity to participate in an interview independently was important to assess for two reasons. First, qualitative interviews depend on having sufficiently rich data to conduct a thematic analysis. One-word responses to interview questions, for example, would yield poor quality data. Therefore, we needed to assess if prospective participants would be sufficiently communicative for our purposes. In addition, we wanted research participants to have privacy from parents or guardians. Therefore, capacity to participate in an interview independently was assessed based on prospective participants’ ability to respond verbally or in writing to three sets of questions. Specifically, the three sets of questions were: (1) Do you have some friends? Can you tell me about them?; (2) What do you like doing together? How did you get to know them? How often do you get together?; and (3) What does being a friend mean to you? How do you know someone is your friend? The two study authors rated respondents *not* on the content of their responses, but on anxiety (0=no obvious anxiety; 1=mild signs of anxiety; 2=marked anxiety throughout assessment), social communication (0=extensive use of verbal or nonverbal behavior for social interchange; 1=some reciprocal social communication; 2-most communication is either object-oriented or concerned with particular preoccupations, or 3=little or no communication with interviewer), quality of social response (0=shows a range of appropriate responses, 1=shows responsiveness to most social contexts but somewhat limited, socially awkward, inappropriate, inconsistent or consistently negative, 2=responses that are restricted in range or inappropriate to the context, 3=minimal or no response), and overall quality of rapport (0=comfortable interaction, 1=interaction sometimes comfortable, but not sustained, 2=one-sided or unusual interaction, 3=the participant show minimal regard for the interviewer or the session is markedly uncomfortable for a significant proportion of the time). Individuals who were scored as 2 or higher on any of these four interaction qualities were not eligible.

Eligible participants were invited to provide consent or assent, and parents were invited to provide consent for minor youth participation. Of 50 individuals interested in study participation, 35 were eligible and 25 enrolled in the study. There were 15 individuals who were ineligible. Of these, two were ineligible due to age, one stated that they would find interview questions distressing, six did not have a close friend, and six were ineligible based on the quality of the screening social interchange. Participants were 48% female, 40% male, and 12% non-binary, 64% White, 8% Hispanic/Latino, 12% multiracial, 8% Black, 8% Asian, 56% had ever been employed, 56% had dating experience. Participant Social Responsiveness Scale (SRS-2) T-scores (mean=92.3, *SD*=11.2) were consistent with autism symptoms in the severe (96%) or moderate (4%) range. Forty-four percent were high school students and 48% were enrolled in college or post-secondary school. None reported that they had an intellectual disability (ID). Seventy-six percent reported ever being diagnosed with anxiety, 72% were ever diagnosed with depression, 60% with ADHD, 20% with learning

disorders other than ADD or ADHD, 16% with post-traumatic stress disorder, 8% with an eating disorder, 4% with bipolar disorder, 4% with oppositional defiance or another conduct disorder, and none reported being diagnosed with alcohol use disorder. Specific data on socioeconomic status was not recorded.

Procedures

The Advisory Board reviewed and gave input on the interview protocol, the eligibility criteria, recruitment methods, and interview procedures during two internet-based meetings with the study co-authors prior to the start of the study. Interested prospective participants contacted the research team, and the researchers scheduled a video meeting to describe the study procedures and screen the individual for eligibility. Those who were eligible were asked for consent or, if a minor, assent. Parent consent was also obtained for those who were minors. Eligible youth that provided consent or assent were scheduled for a 30–60 minute Zoom interview. In order to enhance accessibility for people with different communication needs and preferences, participants were given the option of using video and audio, audio only, or using the Zoom text chat function to conduct the interview. Youth were asked to find a private place for the interview where they could not be overheard by other members of their household. The authors conducted the interviews. A standardized protocol (*i.e.*, list of open-ended questions) was used (Table 1). Interviews were audio-recorded and transcribed. Participants received an email with a \$40 [Amazon.com](https://www.amazon.com) gift card after completing the interview.

Data analysis

We used an inductive content-based analysis method as follows: (1) read through each transcript in order to get a sense of the whole, (2) generated a coding list with codes representing themes that were identified in the data (*i.e.*, first and second authors jointly generated the coding list); (3) all transcripts were double coded; codes were applied to text excerpts by both authors using Dedoose software (Dedoose, 2018); (4) coding decisions were reviewed and interrater reliability was calculated (85%); discrepancies were discussed and consensus codes were applied; and (5) data were explored by code for cross-cutting themes and illustrative quotations for each theme were selected.

Because research, qualitative or quantitative, is never truly objective—the words that we choose to use or record, and the way we interpret participant data, reflect our own biases (Miles & Huberman, 1984)—the prior training and background of the data analysts is relevant. The first author is a White, cis-female, middle-aged, neurotypical person and trained social epidemiologist, has a daughter on the autism spectrum, and has volunteered for the Asperger/Autism Network (AANE) non-profit agency leading a support group for autistic adults. The second author is a White, cis-female, allistic, trained clinical psychologist who has been befriending, providing clinical services for, and conducting research to benefit, autistic people for 11 years.

Results

Five key themes about challenges in maintaining healthy peer relationships were identified. These included that youth found it challenging to: (1) remain motivated to make and maintain friendships; (2) overcome anxiety about making social overtures or continuing relationships, rooted in prior bad experiences with friends; (3) take emotional risks; (4) cultivate reciprocity in relationships; and (5) identify, communicate, and respect sexual and emotional boundaries. In addition, we tabulated their responses to close-ended questions about whether they thought it would be preferable to have the HEARTS class offered to single-gender or mixed-gender groups of students, and whether it should be taught by a neurotypical or autistic teacher, or by a mixed team of one neurotypical and one autistic teacher.

Theme 1: Motivation to make and maintain friendships

Nine participants reported that they felt like they did know how to meet people, and had sufficient basic social skills, but that their challenge in relationships was a lack of motivation to keep the relationship going. For example, one 21-year-old female reported:

“I get along with most people, but [my challenge is] actually staying in touch and making the effort to actually feel like I want to talk to them. Because, I would end up making a friend and then three months later I don’t text them for a while and it just kind of falls apart there.”

(ID51)

For some participants, spending time alone and enjoying free time was a more attractive option than socializing with others, as per this 16-year-old male participant:

“In terms of the skills of getting a relationship, I feel like...I’m pretty good at that. My problem is more like wanting to use those skills or not. I don’t want to have social commitments...Some would say [my challenge is] fear of rejection, but I know it can’t be just that because...sometimes I’m even afraid of [other people saying] yes. I don’t want to have any commitments other than to just hang out by myself doing nothing.”

(ID45)

One 16-year-old girl reported that she forgot to continue to invest in her relationships. She said:

“Sometimes I forget to sort of maintain the relationship... sometimes I’ll, like, go for a month...without like, texting anyone, and then be like, ‘oh, like, what about that [friendship]?’”

(ID9)

She was not the only participant who reported forgetting to maintain friendships. A 22-year-old, non-binary participant also reported struggling to remember to contact friends. They said:

“So I remember a text right when I receive it, but if I set it down to do something else, it vanishes. The same goes for remembering that my friends exist. It doesn’t occur to me that I can reach out to them most of the time unless they contact me, I almost forget that they exist when I’m not spending time with them. I like spending time with them a lot when I am doing so, but I forget that it’s an option in general.”

(ID59)

One 20-year-old male participant had addressed the problem of forgetting to communicate with friends by creating a social checklist, like a to-do list, for himself. He described it this way:

“I try to make sure that [friends] know that I care about them. I actually have a list I use. Every day I have a list of people I want to text or talk to or message them something that day. And, so I can look back at the notebook and say, ‘Oh, I haven’t checked on so-and-so in a while.’”

(ID58)

Theme 2: Overcoming anxiety rooted in prior bad experiences

Interviews revealed that participants often avoided approaching new people for friendship, were reluctant to engage with existing friends and acquaintances, or “ruined” friendships by needing a lot of reassurance because they were anxious about being rejected or being manipulated and abused. In seven cases, negative experiences with peers in elementary and middle school had left emotional scars or created insecurities and anxieties that influenced their capacity to stay centered in friendships. For example, one 17-year-old female participant said:

“Sometimes I get very insecure about my friendships and relationships and half the time that ruins it because I get so insecure because of the past... worrying a lot. And, sometimes it gets a little overwhelming for people. ‘Do you still like me? Are you sure you want to be friends with me?’ That kind of stuff.”

(ID24)

The participant that was 22 years old and non-binary also reported that they often avoided interacting with the friends that they did have because of being told that the way that they interact with other people wasn’t acceptable, which had traumatized them. They said:

“I think another piece is trauma. 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. Most of us have been mistreated due to our ways of interacting and expressing ourselves, and that will likely be something that follows us throughout our lives in many cases, no matter how careful we are about who we keep in our lives”

(ID59)

A 19-year-old male participant reported that while he wrestled with anxiety about approaching new people, he managed to talk himself into doing it by considering the

likelihood that they were going to assault him physically in response, which he thought was possible but unlikely. He said:

“[In order] to not give in to anxiety, or just will myself to [approach], [I say to myself] ‘All right, you know what? It’s not like I’m gonna get stabbed or anything if this does go wrong. Maybe, but that’s like a real small chance. Most likely nothing bad’s gonna happen if this doesn’t work out.’”

(ID10)

Theme 3: Taking emotional risks

Eleven participants with friends and dating partners expressed a desire to learn more about how to deepen healthy relationships—for example, how to take friendships from a superficial level into more emotional intimacy. Discussions about how to feel more closely connected to peers, and experience more trust and cohesion in their relationships, centered around feeling comfortable opening up and making various types of self-disclosures. Knowing when and how to disclose feelings was particularly salient, as was knowing how much to disclose and to whom. One 17-year-old female participant talked about struggling to determine how much to disclose, and how, in her relationships. She said that she believed it was good to “be very vocal about how you’re feeling, right? But, not too vocal. There’s a happy medium.”(ID24).

The importance of expressing oneself in order to have more authentic relationships emerged in participant comments, as well as the idea that trying to conceal one’s true feelings could damage relationships by causing resentment. One 16-year-old female participant explained that in her experience holding back emotions was counterproductive:

“You can’t get far [in a relationship] if you’re holding back, you know? You can’t get far if you’re biting your tongue. All that will just build up and then you’ll explode.”

(ID48)

A 16-year old male participant explained that, in his experience, he was encouraged to be more vulnerable with a friend after the friend first opened up. Importantly, this participant was paying attention to equality or balance in the relationship:

“He told me some personal stuff, so it was like, ‘Alright. I’ll play this game of personal information sharing.’ He was open with me, so it’s like I can be open with him.”

(ID4)

Theme 4: Cultivating reciprocity

Seventeen participants expressed the importance of mutual interest, equality, and balance for relationships. Some participants described how social skills books and classes had focused on the autistic person being a good friend rather than finding people who would be good friends or finding people who were interested in being friends. They learned that having good friendship skills did not always result in everyone wanting to be friends in return –

there was a “chemistry” aspect of friendship that went beyond being a good person, and that it was important to acquire skills to distinguish between healthy and unhealthy relationships. One 19-year-old woman said:

“What I’ve learned is you can be as good of a friend as possible, but it’s not gonna work if the other person isn’t just as interested in being your friend as you are [in] being their friend. And, I did learn that the hard way. There’s definitely been a lot of people that I’ve tried to be good friends to and I’ve reached out and stuff, but they just didn’t reciprocate.”

(ID1).

Initiating conversation or spending time together was a common indicator of mutuality and continuing interest in a developing relationship. A 16-year-old male described how an imbalance in initiation made him increasingly discouraged about a developing friendship:

“I mean, when we were starting out as friends there was some consistency, but then it just kind of became a one-way street and it was me doing all the initiating.”

(ID6)

When a potential friendship or romantic partner does not invest the same time and effort into developing a relationship as the autistic person does, this can cause insecurity, especially if the this is a pattern they notice repeatedly. According to an 18-year-old woman who describe her efforts to make friends,

“It feels like to me that I’m always the person in the relationship asking people like, ‘Hey, do you want to hang out? Do you want to do that?’ And, like do they really want to be my friends if they don’t ask me that ever?”

(ID41)

Once both people are feeling more secure in a relationship, the need for reciprocal give-and-take continues. Participants described emotionally fulfilling relationships that involved both providing and benefitting from various supports. A 17-year-old girl said, “I’m able to support her. She’s able to support me. It’s a give-and-take relationship.” (ID24)

Theme 5: Creating, maintaining, and respecting boundaries

Personal boundaries are limits or rules that a person creates to identify safe and preferred ways for other people to behave toward them and how they will respond when someone passes those limits. Personal boundaries imply that an individual takes responsibility for their own emotions and actions, and does not take responsibility for the emotions or actions of others. While some boundaries are or should be universal, such as choosing who can touch you in a sexual manner, others are person-specific and arise from an individual’s learning history, beliefs, values, and preferences. Boundaries can apply in all types of relationships. Eleven participants commented on boundaries. An 18-year-old woman described an experience when both she and a depressed friend both had difficulty setting healthy boundaries, leading to an unequal dynamic and resentment.

“But then they were struggling through depression and I ended up essentially becoming their therapist. They would call me at all times of the day crying, needing

my help, needing to talk through something, and it became really hard and it was causing me a lot of stress and anxiety. I got them into therapy, but they would still call me and constantly want to talk to me about their problems. And, that would be okay. I mean, not okay to put all of your burdens on someone when they finally get you help, but they never asked how I was doing...I wondered at times if they really knew anything about me...if I said anything [about the unequal dynamic], I felt like they wouldn't be able to piece themselves back together.”

(ID41)

Others described needing to learn how to set and respect sexual boundaries. For example, one 20-year-old woman worried that she had crossed a sexual boundary with an ex-romantic partner who was now a friend. She reported wishing that she had learned more about boundaries in school or previous social skills learning opportunities:

“Especially when I was taking behavior intervention classes in middle school, I think it would have been nice to actually have an in-depth discussion of...how boundaries in dating and in sex work.”

(ID18)

The desire to learn how to set boundaries was echoed by a 16-year-old girl:

“Yeah. I wish I had strategies on how to deal with – not deal with, but how to cope with...how to acknowledge when enough is enough.”

(ID48)

Some participants described the process of learning about boundaries and trust. For example, this 16-year-old girl described some difficulty with coming up with appropriate dating activities that would not place her in situations, such as being alone in an empty house, where her sexual boundaries could be crossed. She said, “I have learned to surround myself with people who will respect my boundaries.” (ID48)

Class composition and teacher preference

All 25 interview participants were asked if the HEARTS intervention should be delivered to single-gender participant groups or to mixed-gender groups. Half (56%, n=14) voted for mixed-gender groups, 20% felt it should be delivered to single-gender groups, 12% thought that participants should be offered a choice, and 12% had no opinion. Most felt that single-gender groups would be problematic because gender non-binary people might feel excluded. In the words of one 17-year-old, non-binary participant:

“Mixed gender is probably good. Particularly because I actually warn against gender divide. Particularly because it solidifies the idea that women or girls should act one way and men or boys should act another. And, it also makes it uncomfortable for trans kids.”

(ID47)

In addition, 24 interview participants provided an opinion about whether they think the HEARTS intervention should be facilitated by a neurotypical person, an autistic person, or team-facilitated by a neurotypical and autistic pair. Sixty-three percent (n=15) voted for

a team-facilitation model, 33% voted for an autistic facilitator, and one had no opinion. The word “condescending” was used by interview participants to describe concerns about how a neurotypical teacher might approach the material. An argument for having a team-facilitation approach was offered by a 16-year-old female participant:

“A neurotypical person would maybe have better experience about how to get things right, they might know more, because part of autism is not knowing, but on the other hand an autistic person would find easier to get across to people, because they get it like they aren’t going to say something sort of offensive. Because sometimes well-meaning neurotypical people can stay stuff that’s like ouch, you don’t understand.”

(ID9)

Discussion

This qualitative research study was designed to be formative research to inform the content of a new intervention (HEARTS) to promote relationship skills for autistic young adults. The process yielded important findings with direct application to the intervention. For example, interviews with autistic youth revealed that many had already learned didactically how to introduce themselves to new people, make friendship overtures, and have been told that they should establish peer relationships. This research uncovered that a separate challenge that some autistic people may face is remaining motivated to maintain existing relationships (Theme 1), and that some may feel acute anxiety about maintaining relationships because of prior bad experiences (Theme 2). This type of negative experience, and resulting anxiety, is not unique to autistic individuals—and importantly—not all individuals who feel low motivation to socialize or social anxiety want or need an intervention to change that. However, as was reflected in comments from some of our research participants, some autistic people who feel low motivation to socialize and social anxiety are interested in intervention participation. And, we anticipate that there will be a benefit of addressing these topics in a workshop designed to be helpful and supportive for autistic participants, specifically. For example, acknowledgement that alexithymia and anxiety related to interpreting social cues can influence how one experiences the process of meeting people, establishing relationships, and maintaining relationships in a group setting where multiple members may have had similar experiences could be both therapeutic and educational. Other themes that were identified from the interviews with autistic youth suggested that the HEARTS workshop should build skills for distinguishing between healthy and abusive relationships, and taking emotional risks (Theme 3), noticing and promoting reciprocity in relationships (Theme 4), and establishing and respecting boundaries (Theme 5). Offering the workshop to mixed gender audiences, and having it co-facilitated by a neurotypical and autistic adult as a pair, also emerged as stakeholder recommendations.

Prior research has demonstrated that the social networks of autistic adults may be enhanced through classes and low level community interventions, such as providing one-to-one personalized support and opportunities to participate in peer groups and social activities (McConkey et al., 2021). In addition, cognitive behavior therapy (CBT)-type approaches have been found to be effective for social anxiety and to improve social motivation (Bemmer

et al., 2021), and interventions such as PEERS and Circles have been found to improve friendship quality and conversational skills in adolescents and young adults ages 15–26 years old (Rose et al., 2021; Wyman & Claro, 2020). Job-based social skills interventions have also been found to improve autistic adults' social-pragmatic skills such as social awareness, reciprocal social communication, and social avoidance (Gorenstein et al., 2020). However, none of these prior approaches focus exclusively on relationship skills such as discerning healthy, supportive friends and dating partners from abusive or unhealthy ones, or setting boundaries with friends and partners, or knowing how to end a friendship or break up with a dating partner in a healthy, safe way if needed—which are all topics that were indicated from the present, formative research. Moreover, none of the prior interventions are co-delivered by a non-autistic and autistic facilitation team. Therefore, the HEARTS intervention will fill a needed gap in the field by addressing relationship skills—instead of only social pragmatics, management of social anxiety, reciprocal social communication and conversational skills—and by breaking new ground in terms of non-autistic and autistic co-facilitation teams. Specifically, consistent with the results of this formative research and input from the Advisory Board, the HEARTS intervention will cover: (1) Defining healthy vs. unhealthy relationships; (2) Relationship challenges; (3) Relationship anxiety and neurohealth; (4) Establishing new relationships; (5) Communicating boundaries; and (6) Ending relationships.

It will be important to test the impact of HEARTS using rigorous methods. It is presently being pilot-tested for feasibility using a one-group pre- and post-test design with a small sample of participants; if it is promising, it should be tested through a large-scale randomized controlled trial (RCT). In general, psychosocial interventions for autistic individuals have often been evaluated using small samples and short-term follow-up, in part because it may have been difficult for researchers to obtain adequate funding for larger-scale RCTs (Bishop-Fitzpatrick et al., 2013). As we enter a new era of support for interventions and services for individuals on the autism spectrum, it will become increasingly important for researchers to generate high-quality and methodologically rigorous evaluation studies that reveal which participants are most likely to benefit from the interventions and how the interventions can be improved to make larger impacts on the lives of autistic people.

This formative research study was limited by several weaknesses. First, as with all qualitative research, it is possible that the autistic individuals that we interviewed had opinions and life experiences that diverge from other autistic individuals. The purpose of qualitative research is not to elicit generalizable results but nevertheless it is important that findings inspire sufficient confidence to be considered useful. We consider the present formative research study a starting point for developing HEARTS and intend to continue to refine the content after pilot-testing. Second, although 28% of the sample identified their race or ethnicity as something other than non-Hispanic White—which means the sample was more racially and ethnically diverse than the majority who participate in autism research, more racial and ethnic diversity would be beneficial. Third, this research took place during the COVID-19 pandemic of 2020. Therefore, some participants' comments about social challenges they faced and meeting new people may have been influenced by recent experiences with extreme social isolation. Fourth, the definition of a close friend was idiosyncratic to this study and included the parameter that a friend is within two years of

one's own age. In retrospect, this definition of friend is too limiting and should be altered for future studies of this nature.

Conclusion

Overall, the results of this multi-step formative research provided rich information that guided the selection of content topics for the six-session HEARTS intervention.

Funding Acknowledgements

Research reported in this publication was supported by the National Institute of Mental Health (NIMH) of the National Institutes of Health under award number K18MH122791. All project costs were financed with federal money. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. We acknowledge Advisory Board members who were involved in the design of the research study, and provided input on youth eligibility criteria, interview questions, and data interpretation.

References

- Bemmer ER, Boulton KA, Thomas EE, Larke B, Lah S, Hickie IB, & Guastella AJ (2021). Modified CBT for social anxiety and social functioning in young adults with autism spectrum disorder [Article]. *Molecular Autism*, 12(1), 15, Article 11. 10.1186/s13229-021-00418-w [PubMed: 33622389]
- Bishop-Fitzpatrick L, Minshew NJ, & Eack SM (2013). A systematic review of psychosocial interventions for adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 43(3), 687–694. [PubMed: 22825929]
- Brown K, Pena E, & Rankin S (2017). Unwanted sexual contact: Students with autism and other disabilities at greater risk. *Journal of College Student Development*, 58(5), 771–776.
- Chou WJ, Hsiao RC, Ni HC, Liang SHY, Lin CF, Chan HL, Hsieh YH, Wang LJ, Lee MJ, Hu HF, & Yen CF (2019). Self-Reported and Parent-Reported School Bullying in Adolescents with High Functioning Autism Spectrum Disorder: The Roles of Autistic Social Impairment, Attention-Deficit/Hyperactivity and Oppositional Defiant Disorder Symptoms [Article]. *International journal of environmental research and public health*, 16(7), 13, Article 1117. 10.3390/ijerph16071117
- Dedoose. (2018). Dedoose Version 8.0.35, web application for managing, analyzing, and presenting qualitative and mixed method research data. In SocioCultural Research Consultants, LLC.
- Gorenstein M, Giseran-Kiss I, Feldman E, Isenstein EL, Donnelly L, Wang AT, & Foss-Feig JH (2020). Brief Report: A Job-Based Social Skills Program (JOBSS) for Adults with Autism Spectrum Disorder: A Pilot Randomized Controlled Trial [Article]. *Journal of Autism and Developmental Disorders*, 50(12), 4527–4534. 10.1007/s10803-020-04482-8 [PubMed: 32297122]
- Lasgaard M, Nielsen A, Eriksen ME, & Goossens L (2010). Loneliness and social support in adolescent boys with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 40(2), 218–226. [PubMed: 19685285]
- Laugeson EA, Frankel F, Gantman A, Dillon AR, & Mogil C (2012). Evidence-based social skills training for adolescents with autism spectrum disorders: The UCLA PEERS program. *Journal of Autism and Developmental Disorders*, 42(6), 1025–2036. [PubMed: 21858588]
- Lebrun-Harris LA, Sherman LJ, Limber SP, Miller BD, & Edgerton EA (2018). Bullying victimization and perpetration among U.S. children and adolescents: 2016 National Survey of Children's Health. *Journal of Child and Family Studies*, 28, 2543–2557.
- Leviton LC, Finnegan JR, Zapka JG, Meischke H, Estabrook B, Gilliland J, Linares A, Weitzman ER, Raczynski J, & Stone E (1999). Formative research methods to understand patient and provider responses to heart attack symptoms. *Evaluation and Program Planning*, 22(4), 385–397. 10.1016/S0149-7189(99)00025-7
- Maïano C, Normand CL, Salvat M-C, Moullec G, & Aimé A (2015). Prevalence of school bullying among youth with autism spectrum disorders: A systematic review and meta-analysis. *Autism Research*, 9(6), 601–615. [PubMed: 26451871]

- McConkey R, Cassin MT, McNaughton R, & Armstrong E (2021). Enhancing the social networks of adults with ASD: a low level community intervention. *Advances in Autism*, 13. 10.1108/aia-07-2020-0043
- Miles MB, & Huberman AM (1984). Qualitative data analysis: A sourcebook of new methods. In *Qualitative data analysis: a sourcebook of new methods* (pp. 263–263).
- Orsmond GI, Shattuck PT, Cooper BP, Sterzing PR, & Anderson KA (2013). Social participation among young adults with an autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 43(11), 2710–2719. 10.1007/s10803-013-1833-8 [PubMed: 23615687]
- Oswald TM, Winder-Patel B, Ruder S, Xing G, Stahmer A, & Solomon M (2018). A pilot randomized controlled trial of the ACCESS program: A group intervention to improve social, adaptive functioning, stress coping, and self-determination outcomes in young adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 48(5), 1742–1760. [PubMed: 29234931]
- Pallathra AA, Cordero L, Wong K, & Brodtkin ES (2019). Psychosocial Interventions Targeting Social Functioning in Adults on the Autism Spectrum: a Literature Review [Review]. *Current Psychiatry Reports*, 21(1), 11, Article 5. 10.1007/s11920-019-0989-0 [PubMed: 30734097]
- Rose AJ, Kelley KR, & Raxter A (2021). Effects of PEERS(R) Social Skills Training on Young Adults with Intellectual and Developmental Disabilities During College [Article]. *Behavior Modification*, 45(2), 297–323, Article 0145445520987146. 10.1177/0145445520987146 [PubMed: 33423534]
- Roux A, Shattuck P, Rast J, Rava J, & Anderson K (2015). National Autism Indicators Report: Transition into Young Adulthood.
- Sreckovic MA, Brunsting NC, & Able H (2014). Victimization of students with autism spectrum disorder: A review of prevalence and risk factors. *Research in Autism Spectrum Disorders*, 8(9), 1155–1172.
- U.S. Department of Health and Human Services. (2017). Report to Congress: Young Adults and Transitioning Youth with Autism Spectrum Disorder. <https://www.hhs.gov/sites/default/files/2017AutismReport.pdf>
- Vernon TW, Miller AR, Ko JA, Barrett AC, & McGarry ES (2018). A randomized controlled trial of the Social Tools and Rules for Teens (START) program: An immersive socialization intervention for adolescents with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 48(3), 892–904. [PubMed: 29164444]
- White SW, Ollendick TH, Albano AM, Oswald D, Johnson C, Southam-Gerow MA, Kim I, & Scahill L (2013). Randomized controlled trial: Multimodal Anxiety and Social Skill Intervention for adolescents with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 43(2), 382–394. [PubMed: 22735897]
- Wyman J, & Claro A (2020). The UCLA PEERS School-Based Program: Treatment Outcomes for Improving Social Functioning in Adolescents and Young Adults with Autism Spectrum Disorder and Those with Cognitive Deficits [Article]. *Journal of Autism and Developmental Disorders*, 50(6), 1907–1920. 10.1007/s10803-019-03943-z [PubMed: 30820726]

Table 1.
Example interview questions

Topic	Example questions
Establishing healthy relationships	(a) Think about some of the relationships in your life that you enjoy and make you feel happy and supported. Who are they with? How did you meet them?
	(b) What kinds of things do you do that make these relationships healthy and successful?
	(c) What is it about the other person that makes them a good friend or partner?
Challenges in social relationships	(a) When you think about your social life right now, what are the biggest problems that you are facing?
	(b) Sometimes relationships don't work out quite right, and that happens to everyone. If you've ever had a friendship or another type of relationship that ended even though you didn't want it to, what do you think made that happen?
Possible gaps in existing social skills information	What kinds of things have you been taught by a teacher, counselor, class, book or a TV show about friendships, other relationships, or dating that really helped you
	What kinds of problems do you experience with social skills that no teacher, no counselor, no class, no book, and no TV show or movie has ever helped you with?

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript