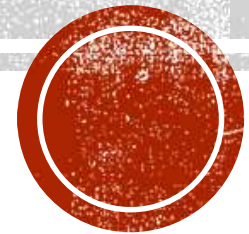


SEX MATTERS: THE UNIQUE PRESENTATION OF AUTISM IN FEMALES AND OVERVIEW OF THE GIRLS NIGHT OUT MODEL



T. Rene Jamison, PhD

Center for Child Health & Development, University of Kansas Medical
Center

National Autism Conference, August 7, 2018

CENTER FOR CHILD HEALTH AND DEVELOPMENT (CCHD) UNIVERSITY OF KANSAS MEDICAL CENTER

CCHD MISSION: *“To advance the health, development, and well-being of children at risk or who have developmental disabilities and supporting their families through:*

- Exemplary clinical service
- Interdisciplinary leadership training
- Outreach training & technical assistance
- Collaborative academic research



WHAT YOU CAN EXPECT...YOUR VISUAL SUPPORT

Autism prevalence and sex differences

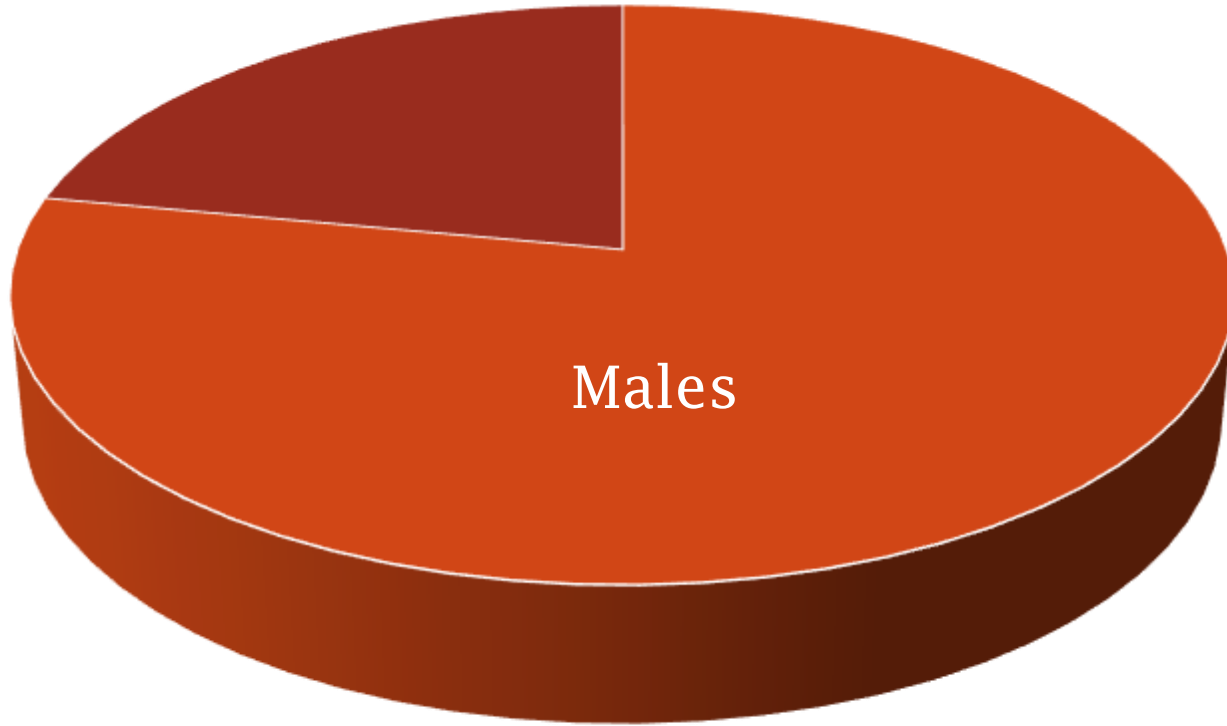
Sex matters (regardless of autism)

Implications for females with ASD

Overview of Girls Night Out (GNO)

Kansas program and initiative for girls

Greater prevalence in males



4:1 - Male to Female Ratio

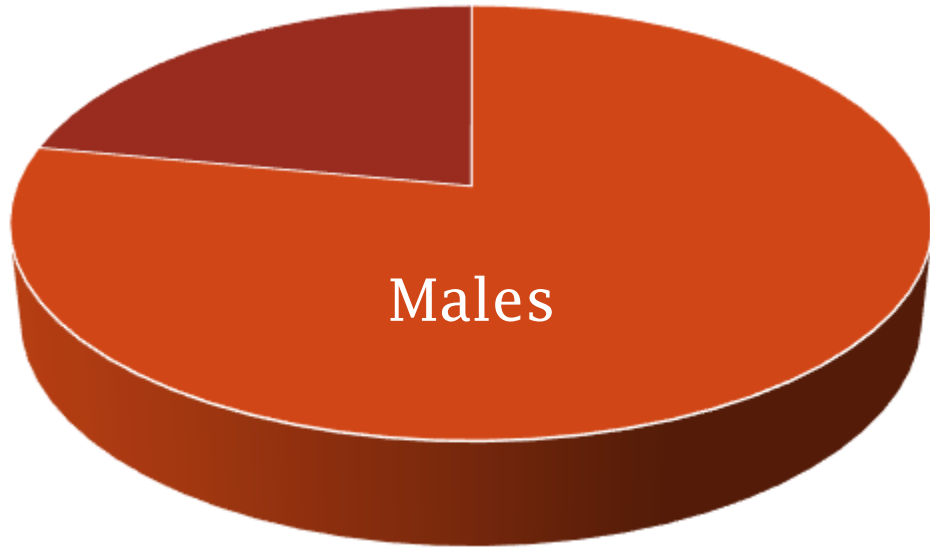
1 in 38 males

1 in 152 females

(1 in 59; CDC *Surveillance
Summaries* / April 27, 2018 /
67(6):1-23



Greater prevalence in males



Lesser impact on females in general population → decreased focus → "female"



SEX DISPARITY IN DIAGNOSIS

Female Protective Effect - ASD result of multiple risk factors

- Females may require larger “load” for ASD threshold (Lai et al., 2014).

Under-representation of females

- Higher functioning females “missed”
- Population studies suggest ~ 2.5-3:1
- More likely not to receive diagnosis, delayed (~ 2 years), misdiagnosis (Rivet & Matson, 2011).



Demographics	N (%)	Mean age (range)	Co-existing Internalizing	Co-existing Externalizing
Females	255	6.43 (1-20)	14 (6%)	77 (34%)
ASD	115 (45%)	6.03* (1-20)	3 (3%)	21 (20%)
No ASD	140 (55%)	6.75 (1-18)	11 (9%)*	56 (46%)*
Males	1021	6.10 (0-21)	55 (5%)	432 (42%)
ASD	532 (52%)*	6.03* (1-21)	29 (6%)	158 (30%)
No ASD	489 (48%)	6.18 (0-18)	26 (5%)	274 (56%)*
Total Sample	1276	6.17 (0-21)	69 (5%)	509 (40%)
ASD	647 (51%)	6.03 (1-21)	32 (5%)	179 (28%)
No ASD	629 (49%)	6.30 (0-18)	37 (6%)	330 (52%)



SEX DIFFERENCES IN ASD

Research on sex differences reveal mixed findings

- Early studies identified females with ASD more likely than males to have co-occurring ID. Recent studies suggest higher functioning girls may be “missed” or present differently.
- Reviews & meta-analyses reveal both similarities & differences between males and females with ASD, with variability across age ranges, cognitive ability and co-occurring conditions.

Consistent themes

- More subtle social difficulties, better conversation and imaginative play skills (early on)
- Males tend to demonstrate more pronounced RRBIs
 - Different presentation in females?
- Exacerbated symptoms during adolescence (social impairments, internalizing symptoms)



Camouflaging: The **masking** of autism behaviors in social situations
and/or

the performance of behaviors to **compensate** for difficulties associated with autism

“Putting on my best normal” , Hull et al. ,2017

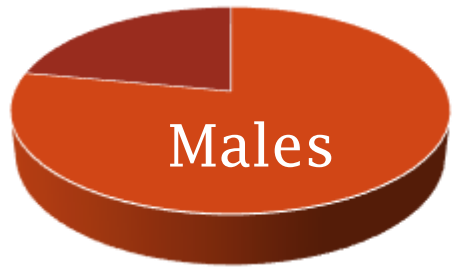
Females more likely to “camouflage” than males

*Experiences of late-diagnosed women with autism....*Bargiela, Steward, & Mandy, 2016

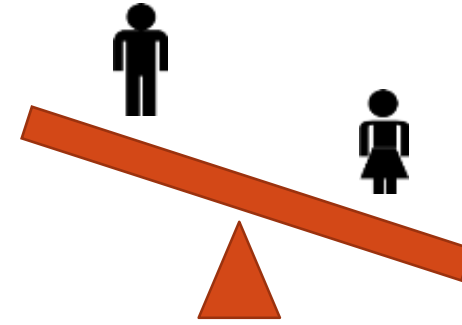
Greater vulnerability to emotional difficulties, including eating disorder;
Mandy et al., 2012

Mandy et al., 2012; Mandy & Tchanturia, 2015; Lai et al., 2011; Lai et al., 2015; National Autistic Society ‘Autism in Pink’ project





Published Research



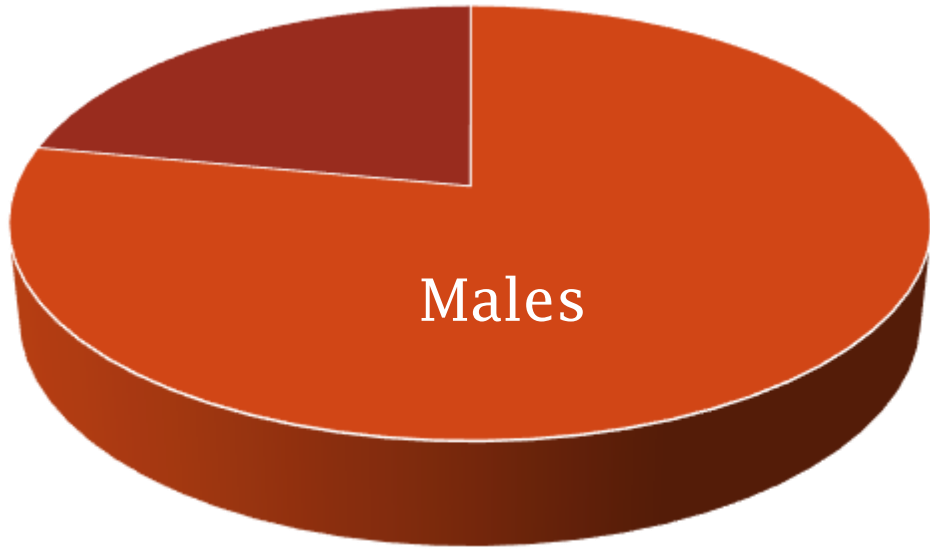
82% of participants in published research studies are male

Potential Implications

- Tools→Diagnosis→Prevalence
- Limits knowledge about girls
- Outcomes and generalization



Greater prevalence in males



Secondary Impact

Greater proportion of males in programs and interventions developed based on male samples



EXAMPLE CLIPS



Sex differences in social-communication



Greater use of nonverbal communication



Conversational skills

Earlier pretend & imaginative play



Empathy



Layers of Complexity

Adolescence

Female

Autism

**Increased social difficulties
and risk for anxiety and
depression**



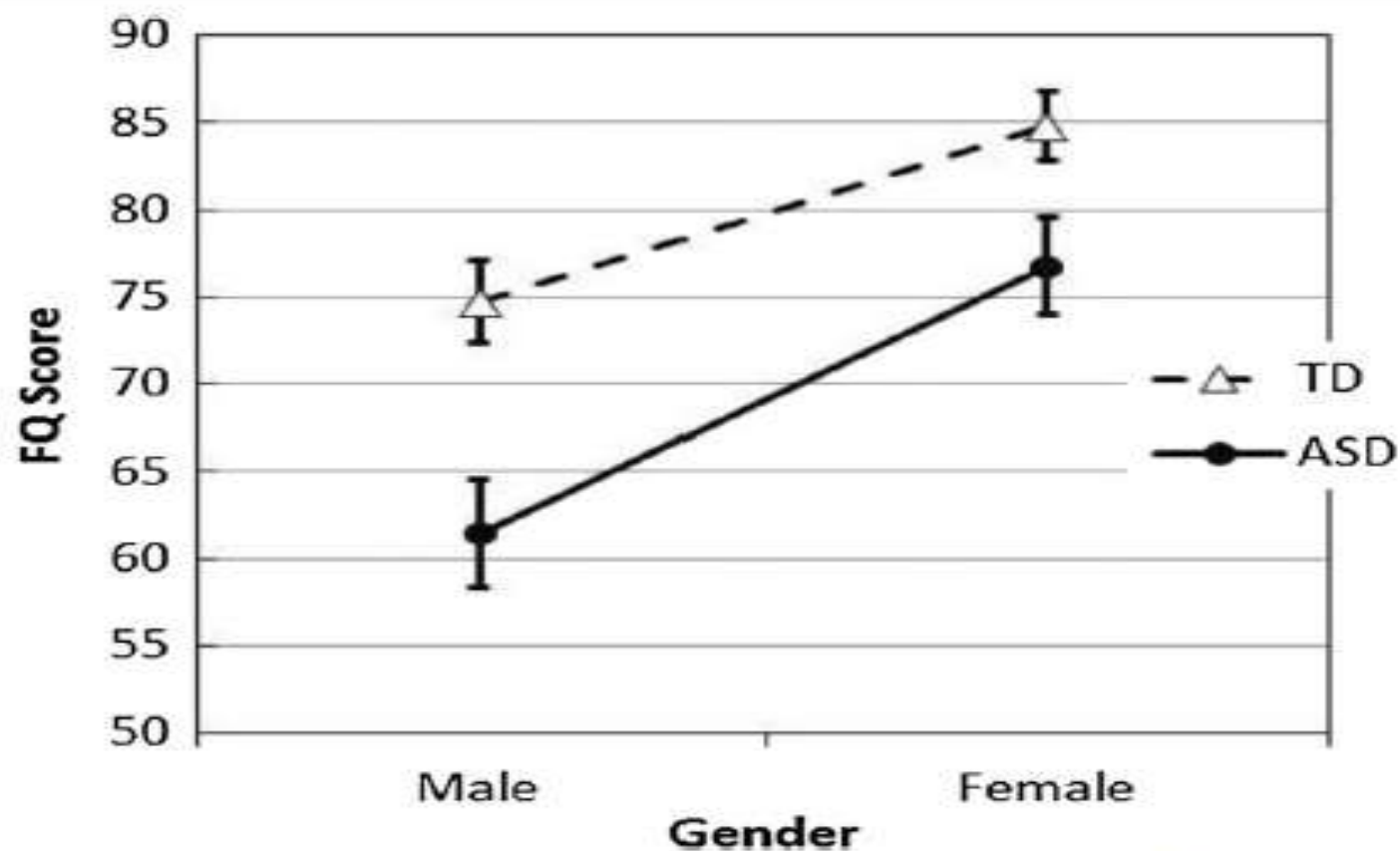


Figure 1 Total friendship questionnaire (FQ) scores by gender and diagnosis. Error bars represent standard errors of the mean. ASD, autism spectrum disorder; TD, typically developing.

CONSIDER REFERENCE GROUP

Individuals with autism scores below that of those without ASD

Girls with autism scored similar to boys WITHOUT autism.

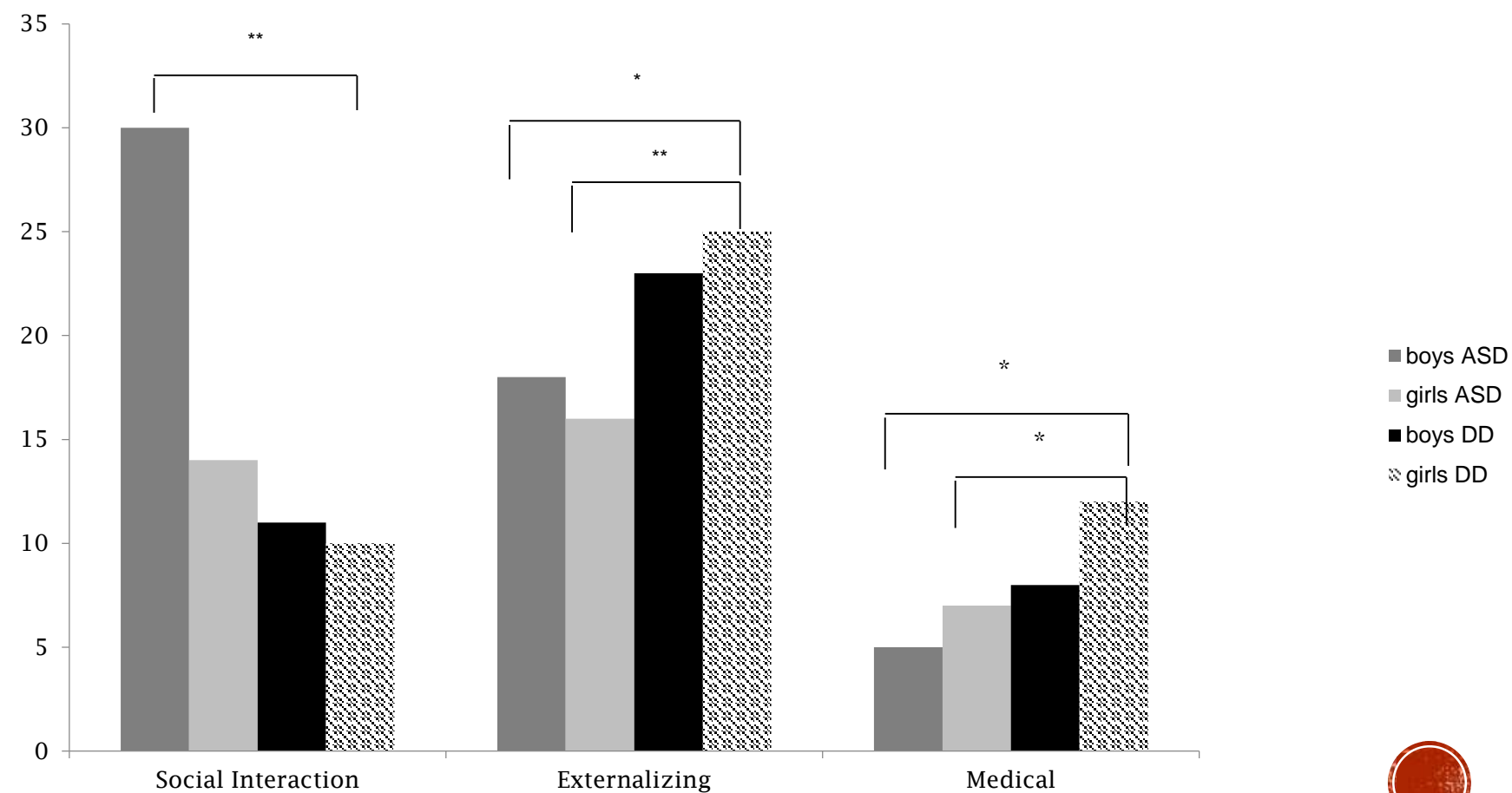


Do early caregiver concerns differ for girls with autism spectrum disorders?

Autism
1-5
© The Author(s) 2014
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sagepub.co.uk/journalsPermissions.nav
DOI: 10.1177/1362361314664188
aut.sagepub.com


Lauren M Little, Anna Wallisch, Brenda Salley and Rene Jamison

Caregiver Concern Differences by Group



EXPLORING THE SOCIAL PROFILE OF FEMALES WITH AUTISM

Research Questions:

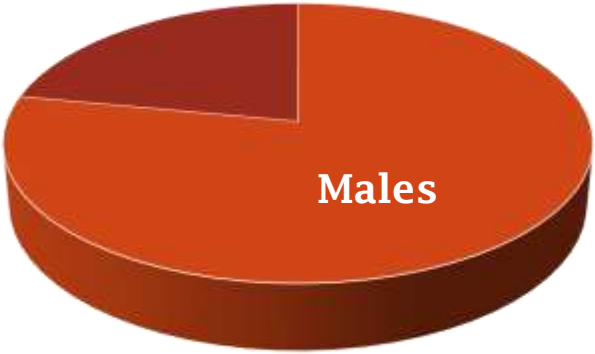
- How are the interests and social activities of adolescent girls with ASD similar or different from their typically developing peers?
- What are the perceived components of and roles within friendships as described by adolescent girls with and without ASD?
- How do social presentation activities and perceptions (e.g. self-care routines) differ in adolescent girls with and without ASD?

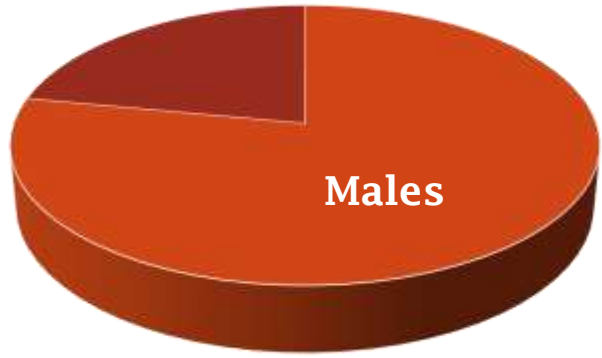
Participant Type	Focus Groups	Total Number	Mean Age (SD)
Adolescent Females with Autism	4*	14	15.57 (1.22)
Adolescent Girls without Autism	4	20	15.85 (1.30)
Parents of Girls with Autism	4*	15	NA
Parents of Girls without Autism	2	12	NA

Schuttler et al.,
manuscript in
progress



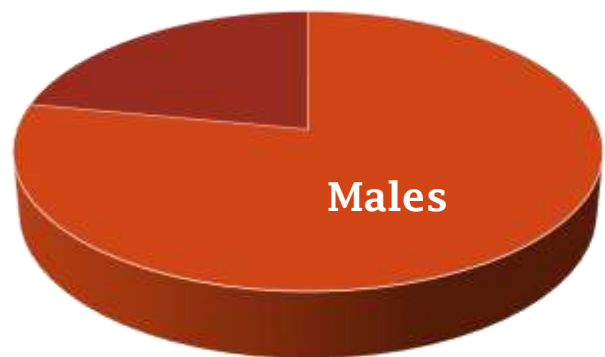
Themes	Supporting Quotes
Limited Social Opportunities and Interactions	<p>“She will plan with a friend several times, but it’s been like gaps, you know. You’re talking about one or two times a year, you know.” (PA)</p> <p>“What our daughter, it seems like she may have a few little friends when she was a little younger, but now it seems like the older she’s getting she’s less and less friends.” (PA)</p> <p>“I’d say she has online friends, that’s it. She likes to...yeah, that she plays games with and...Virtual friends.” (PA)</p>
Planning & Coordination Shift	<p>“There is a vicious cycle that happens - you want to get in on the group activities, and when you attend those activities, you make plans for the next activity - sort of a FOMO effect - you want to attend so you know whats happening next you stay in the "group" and in the "loop.“ (NA)</p> <p>“...so you’re hanging out with like your high school friends and oh like my grade school friends want to do something, .. we all do something and meet each other.” (NA)</p> <p>“my parents drive her we go and get her and then to go to the movies and then her mom usually takes me home sometimes.” (FA)</p> <p>“She wouldn’t invite the kids, but she would direct me to organize with the parents.” (PA)</p>
Increased Complexity	<p>“Well elementary school, it was more of like a small world to me, but when you get to high school it’s a much more bigger world, there’s more different people and it’s more complicated and in high school you have more complicated relationships. “ (FA)</p>





Ascertainment
bias

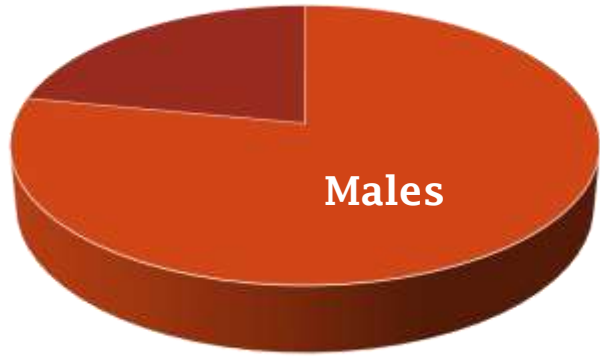




Ascertainment
bias

IV
Generalizability
?



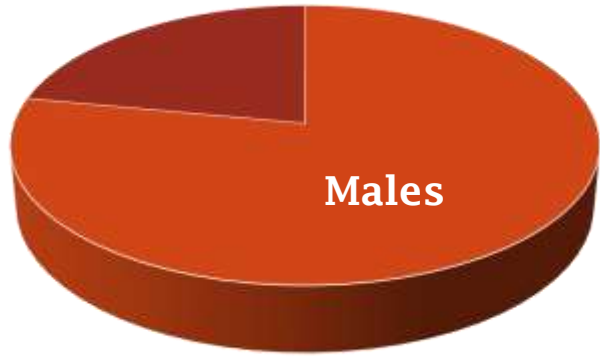


Limited peer
pool

Ascertainmen
t bias

IV
Generalizability
?





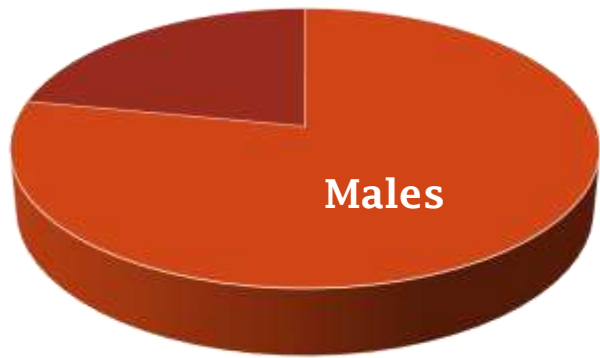
Limited peer
pool

Ascertainmen
t bias

Gender nuanced
skills

IV
Generalizability
?





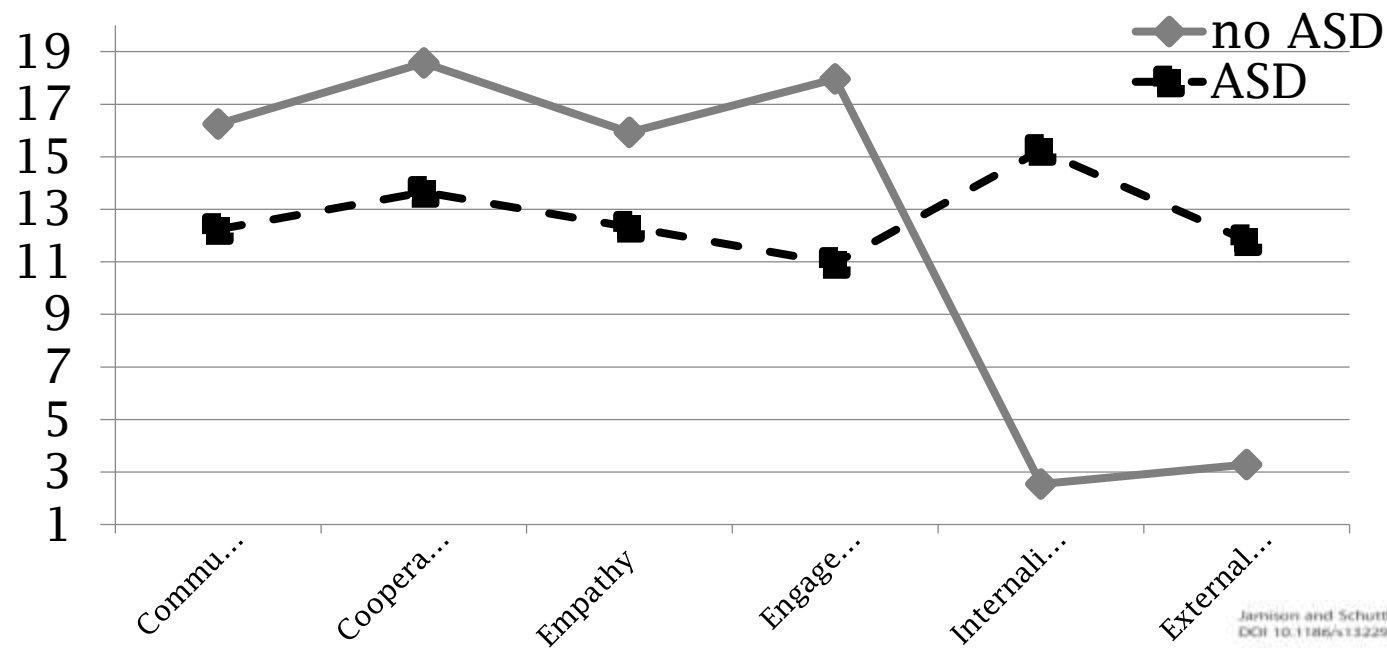
Limited peer pool

Ascertainment bias

Gender nuanced skills

IV
Generalizability
?

→ *Exacerbated* social communication challenges, heightened risk for internalizing symptoms

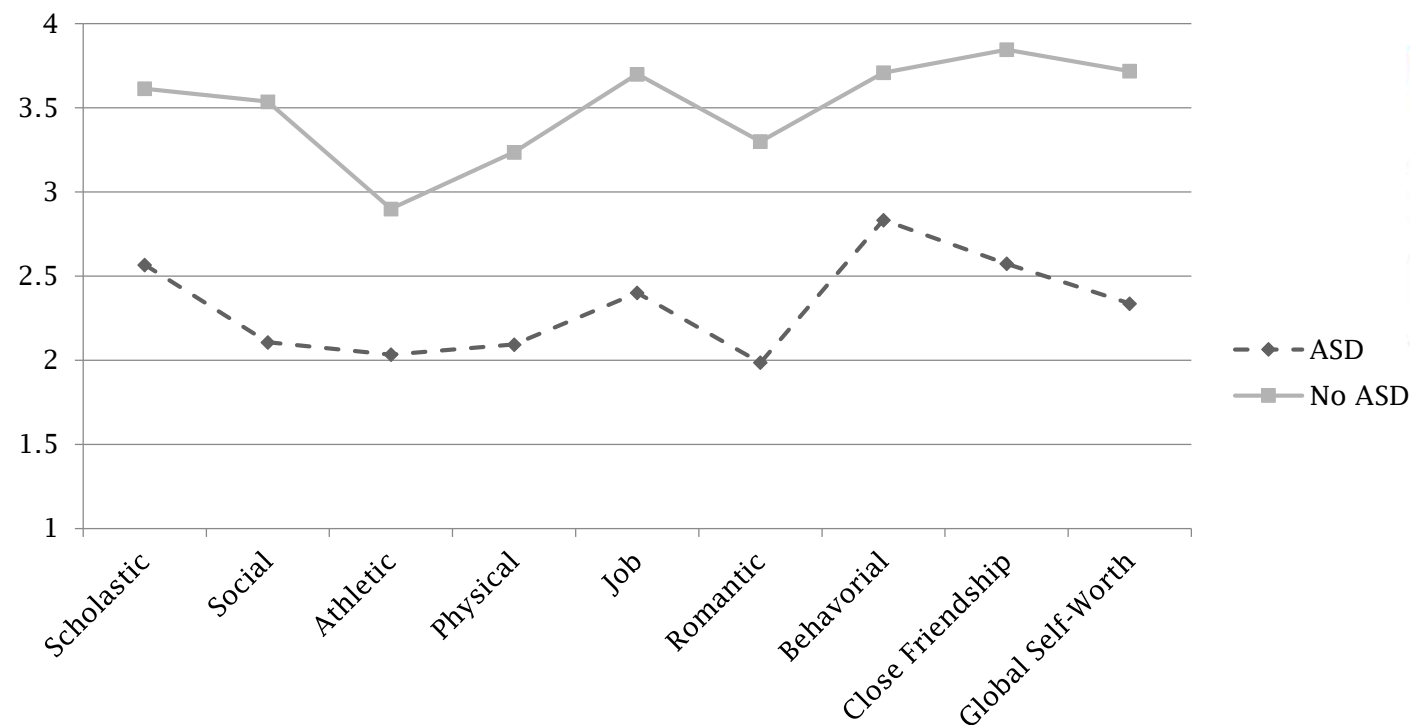


RESEARCH

Open Access

Examining social competence, self-perception, quality of life, and internalizing and externalizing symptoms in adolescent females with and without autism spectrum disorder: a quantitative design including between-groups and correlational analyses

Jamison & Schuttler, 2015



Adolescent girls with ASD evidenced significant internalizing symptoms compared to boys with ASD and TYP girls. –Solomon et al., 2012

Adolescence

Female

Autism

**Increased social difficulties
and risk for anxiety and
depression**

**A unique intervention to address complex needs of adolescent girls with
autism**

ORIGINAL PAPER

Overview and Preliminary Evidence for a Social Skills and Self-Care Curriculum for Adolescent Females with Autism: The Girls Night Out Model

T. Rene Jamison¹ · Jessica Oeth Schuttler¹



PROGRAM OUTCOMES

Improvements in social-communication skills, self-perception, and quality of life.

Satisfaction with program activities and outcomes.

Services and Connections



WHAT MAKES GNO UNIQUE?

- Targets adolescent females w/ ASD!
- Social skills & self care curriculum unique to girls/women.
- Skills taught & practiced within naturally occurring, age relevant activities and settings.
- “Peer mediated”
- Utilizes empirically based strategies
- Focuses on strengths & empowerment.
- Includes formative & summative assessments
- Establishes partnerships w/ community
- **Buy in!!!!**

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PROGRAM STRUCTURE

Participants:

- ~ 4-5 girls with Autism / related diagnosis (14-19 years old)
- ~ 4-6 peer volunteers (screening)

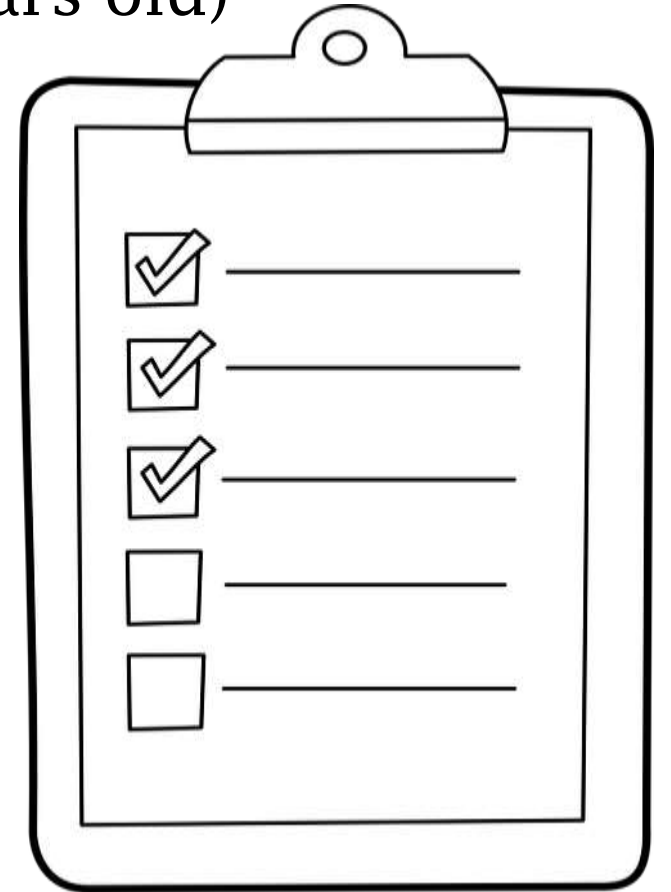
GNO-Teen

Dosage:

- 2 hour sessions
- Weekly for 10-16 weeks

Intervention Procedures:

- General outline
- New theme or activity each session.
- Teach and practice core curriculum concepts in each



Meaningful Experiences

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Core curriculum components

- Relationship building skills
- Promoting independence in self-care
- Building self-determination

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GNO Session Model

Introduction of Skill
(Direct instruction,
video modeling, role
play)



Reinforcement of
skill(s) in age
appropriate activities
& settings



Practice / reinforce /
build on previous
skills



GNO Session Format

- ❖ Facilitator meeting, preparation, community partner training
- ❖ Peer training
- ❖ GNO Opening activities
 - GNO “business” (distribute conversation keyring topics, pay people with GNO bucks for WIDTW sheets, planners, HW).
- Social time (review conversation topics, facilitators provide specific feedback paired with GNO bucks).
- ❖ Follow up on homework
- ❖ Planned activity or lesson (teach, practice, community partner consult)
- ❖ Practice during social or self-care activity with in-vivo coaching, specific feedback, & GNO bucks to reinforce target skills.
- ❖ Data collection
- ❖ Closing Activities
 - Shop at GNO store (token economy)
 - Group picture & community partner thank you (if applicable)
 - Homework: assign My GNO Friend, review new homework
- ❖ Facilitator debriefing
 - Integrity checklist, participant notes, next session plans



Social Learning Theory (SLT)		Behaviors and new skills are learned through observation of others (Bandura, 1971)	Cognitive-Behavioral Theories (CBT)		Behaviors and skills learned by understanding emotional and cognitive interpretations of events, with cognitive and behavioral rehearsal of appropriate behaviors (Kendall, 2006).
	Peer Mediated	Peer mediated approaches (trained peers) are more effective than merely including peers, with best results when instruction occurs in the natural settings and within the context of peer groups (Kamps et al., 2002; White, Koenig, & Scahill, 2007).		Self-monitoring	Participants identify personal goal behaviors related to self-care and social skills and track engagement in behaviors and progress towards goals throughout program (Shapiro, Durnan, Post, & Levinson, 2002).
	Video Modeling (VM)	VM is efficacious for teaching social-communication skills and adaptive behavior among individuals with ASD, including maintenance and generalization to other settings (Bellini and Akullian, 2007).		In-vivo coaching with specific feedback	Using differential attention (Pemberton, Borrego, & Sherman, 2013) with some prompting to encourage desired behaviors, followed by specific praise for engaging in desirable behaviors.
	Modeling & Role Play	Facilitator or peer demonstration of skills. Role plays include practice situations & feedback on skill use. Role play may be used to teach or assess skills (Ratto, 2010).	Behavioral Theories (BT)		Behaviors and new skills are learned through positive reinforcement and environmental contingencies(Thorndike,1913; Skinner, 1988)
	Visual Supports	Tools that help individuals organize and complete activities and tasks by presenting information such as schedules, prompts or cues visually (Johnston, Nelson, Evans, & Palazolo, 2003).		Goal Setting & monitoring	Self-monitoring strategies may increase the use of numerous targeted skills among individuals with ASD (Hume Loftin, and Lantz, 2009).
				Task analysis	Breaking down a task into smaller, component parts that are taught and practiced individually, then combined (Franzone, 2009).
				Token Economy	Positive reinforcement paired with tangible reinforcers (“GNO bucks”) which can be exchanged for desired items (Atyeo and Forchuck, 2013).
				Reinforcement of target skills	Positive reinforcement of desired behaviors is effective in increasing desired behaviors during social skills training. (Gresham, Sugai, & Horner, 2001)

MEET AND GREET: SESSION ONE

Overview and the “Stuff” we use in GNO

Outline

Peer training

Step in or stand up

The stuff



Audience Participation Activity: Example convo starters (find out about person, talk about where you are and what you are doing)

“what brought you to the conference?”

“Have you ever been to this conference before?”

“What kind of work to you do?”

“what afternoon session will you attend?”

“Any plans for your time in State College?”

“Where do you work? What type of setting are you in?”



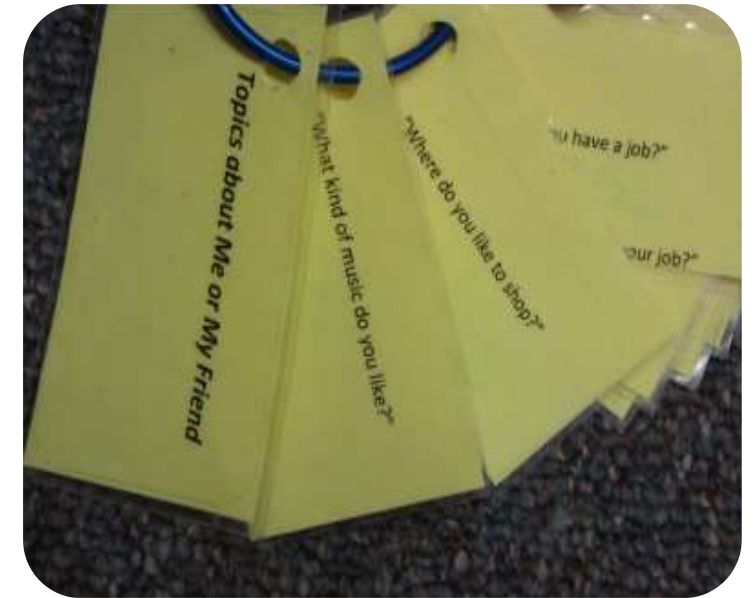
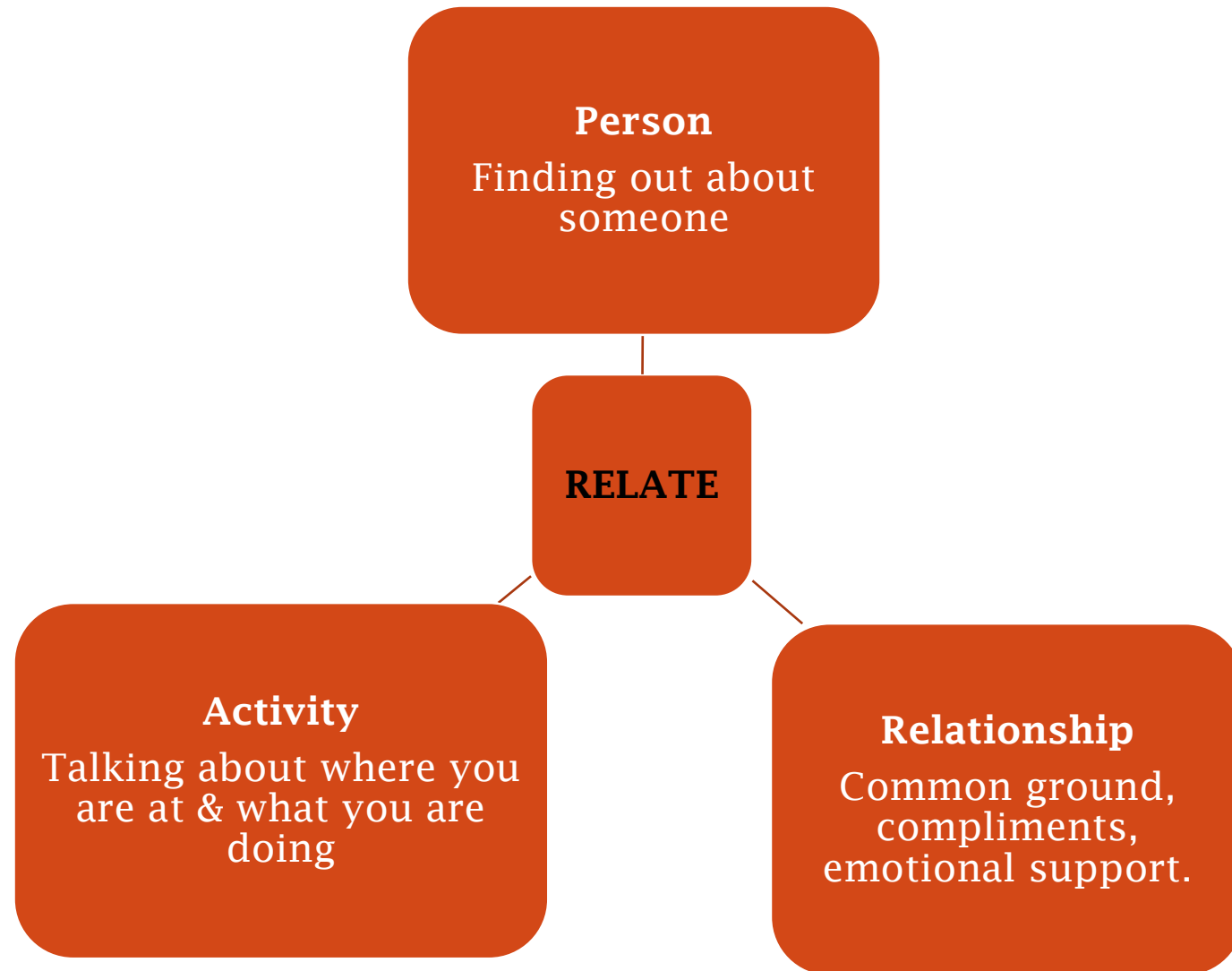
CORE CURRICULUM COMPONENTS AND EXAMPLE SESSIONS

Relationship-building skills

- Conversation “entry” skills.
- Finding common ground
- Making plans
- Emotional support



RELATIONSHIP-BUILDING: *CONVERSATION ENTRY SKILLS*

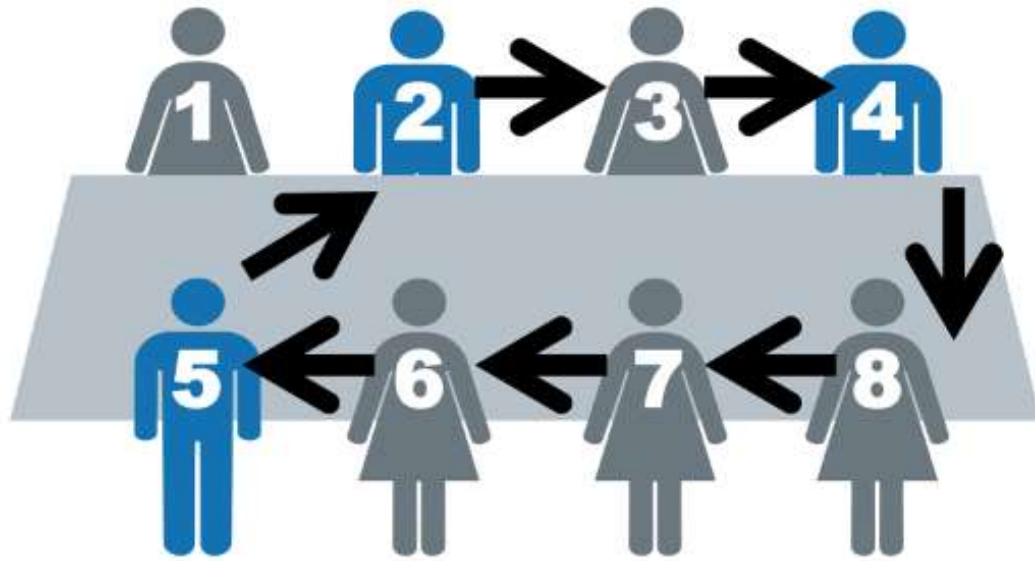


Video model: Finding out about friends.



FINDING COMMON GROUND

Peer Training



The PEOPLE in My Life

Name: _____

Email Address: _____

Phone Number: _____

About My Friend (Ex. Interests, Favorites, Family, Birthday)	Things We Have In Common (Ex. Music, Hobbies, and Sports)

Name: _____

Email Address: _____

Phone Number: _____

About My Friend (Ex. Interests, Favorites, Family, Birthday)	Things We Have In Common (Ex. Music, Hobbies, and Sports)

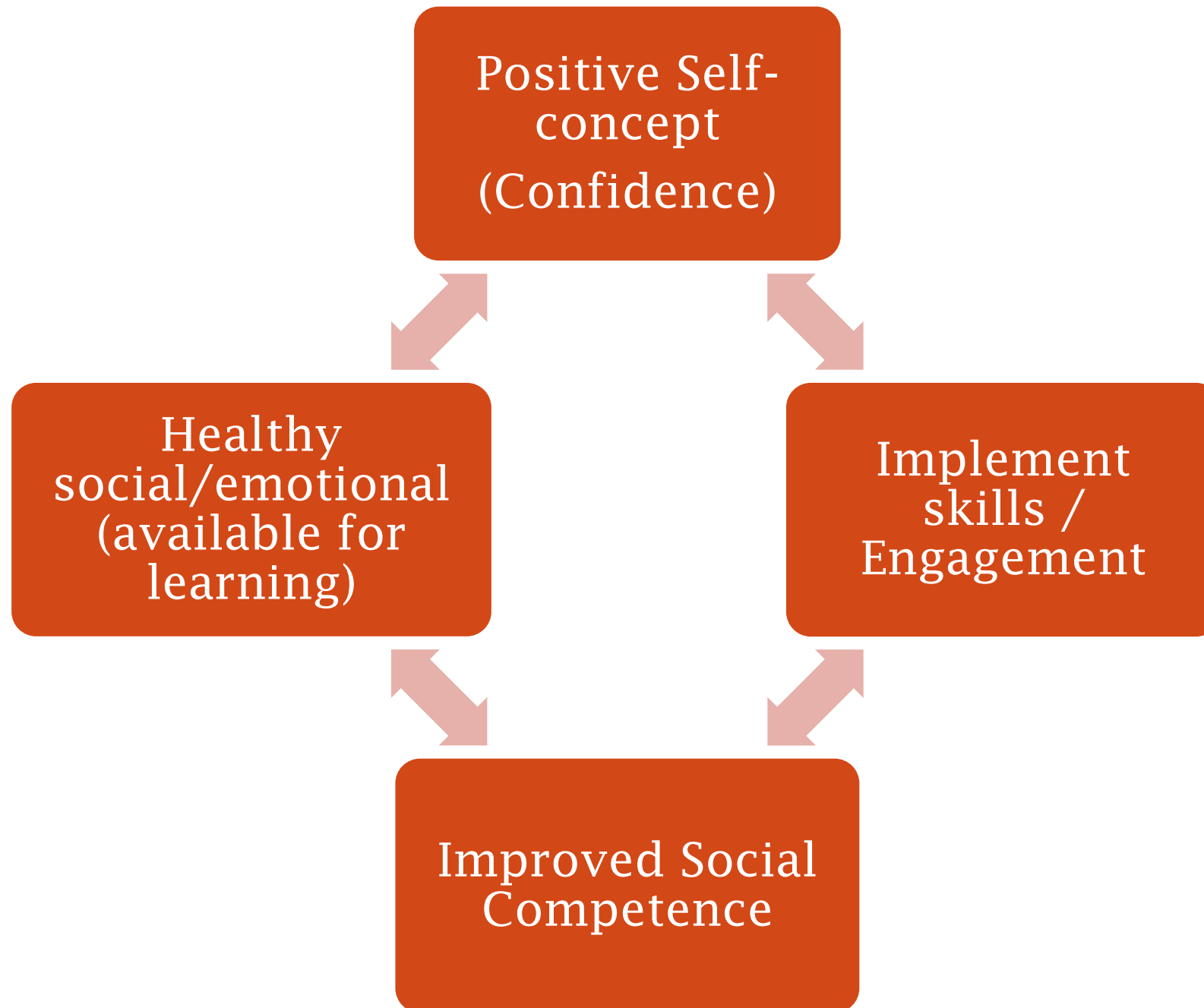
79



PROMOTING INDEPENDENCE IN SELF-CARE SKILLS

- Clothing selection
- Body care (hygiene)
- Skin care
- Hair care
- Health (fitness, nutrition)







GNO: Get Social Girl!

Fashion Session Outline-Facilitator Copy

5:00-6:00 Set up for GNO & facilitator meeting

Review outline, assign roles, review participant and peer target behaviors, set up materials.

5:30-6:00 Peer Training

- Review session outline
- Obtain input on current clothing trends, dos/don'ts, potential needs for group, etc.
- Review "test your outfit" activity and peer roles. How do they make sure fits appropriately, plant question or comment if needed, discuss key points of Gabby's getting ready.
- Model participation in test your outfit activities, encourage trying something new, seek out opinions of participant partner, provide suggestions and feedback during "shopping" activity.
- Model use of GNO supports (planners, keyrings, etc).
- Review homework and importance of contacting them and going through Gabby's getting ready prior to next session. Encourage texting and pics to GNO friend and others.

6:00-6:15 GNO Initial Activities & "Business"

- Distribute GNO bucks for bringing homework, planners & WIDTW sheets as girls arrive –
- Unstructured conversation practice & distribute session supports
 - Conversation key rings; Gabby's getting ready guide & fashion trends visual supports in planner.
 - GNO bucks & specific feedback for conversation. Focus on Relate to the person and activity (PA).
 - Girls can shop at GNO store and look at clothing.

6:15-6:25 Relate introduction and practice: Relating to the Person and the Activity (PA)

- Brief overview followed by Relate to person and activity iPad presentation in small groups
 - Girls partner up and go through Keynote presentation on iPad (content, examples, & video clip)
 - Conversation practice using keyrings for topic ideas
- Data collection (questions, comments, and content type (PAR) during 1 minute practice scenarios

6:25-6:40 Homework & Partner Activity

- Very brief review homework from last week (sit by My GNO Friend if possible)
 - Who contacted their My GNO Friends? Anyone come up with GNO store ideas?
 - Partner Activity: Partner with GNO Friend and do WIDTW sheet for today by talking it out with them.
 - Facilitators mill around to make sure people doing correctly and quickly.
 - Make sure everything is ready for TV presentation, clothes, etc.
- Review purpose of key rings

6:40-7:10 Clothing in context presentation (whole group)

- IPAD presentation on TV: Gabby's Getting Ready (guide for deciding what to wear) –15 minutes
 - Test your outfit activity: Example scenario & practice.
- IPAD presentation: Spring and Summer Trends 2014 (15 minutes)
 - Discuss trends via IPAD and clothing examples-Community Partner
 - Creating outfits with basics and trends-Community partner demonstration



What's the weather like?

Where will I be going?

What will I be doing?

Who's going to be there?



STRETCH YOU LEGS!



my routines

morning



- ☐ Brush my teeth
- ☐ Wash my face
- ☐ Put on deodorant
- ☐ Put in my contacts
- ☐ Put on my makeup
- ☐ Style my hair
- ☐ Floss my teeth

Evening



- ☐ Take out my contacts
- ☐ Brush my teeth
- ☐ Floss my teeth
- ☐ Shower
- ☐ Wash my face

What will I wear?

What parts of my body will show?

What do I need to do to get my body ready?





DOING MY HAIR!!



Make sure it's

CLEAN!

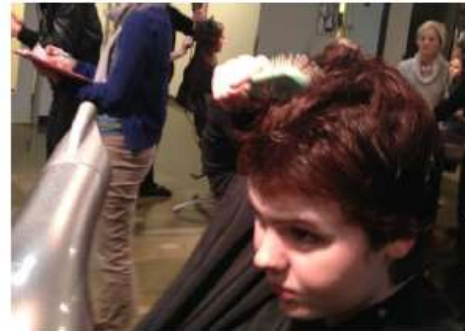
(I should wash my hair every day or every other day)

1. Wash hair with shampoo and conditioner.
2. Comb hair to get out tangles.
3. Add a small amount of product like *Thicken Up*.
 - a. Use fingers.
 - b. Add to bottom and move to top.



DRY it!

1. Point the blow dryer so your hair goes in the opposite direction than you want to wear it.
2. Brush forward on the sides.
3. Lift up the hair on top with the brush.



STYLE it!



BODY STYLE

1. Use flat iron to smooth ends
2. Smooth small chunks
3. Smooth to opposite side of part
4. Brush over with correct part
5. Use shaping cream to finish look
6. Use product to create "spikey" look

Teasing for Body

1. Use fine tooth comb
2. Grab small sections of hair
3. Half way up, comb down 2-3 times
4. Comb 2-3 more times closer to bottom (by skull).
5. Gently comb hair back down or towards part.
6. Use hands or brush to finish look.



BUILDING SELF DETERMINATION

- Identify personal strengths and areas of growth.**
- Goal setting & monitoring**
- Promote independence in activities and skills**

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Date	I did a club or group activity	Self-care activities I did on my own (or without much help)			I did physical activity or other exercise	I called/texted a friend		I hung out with a friend outside of school	Parent Reviewed (initials)
		Pick out clothes	Fix hair	Makeup or skin care		Chat	Make Plans		

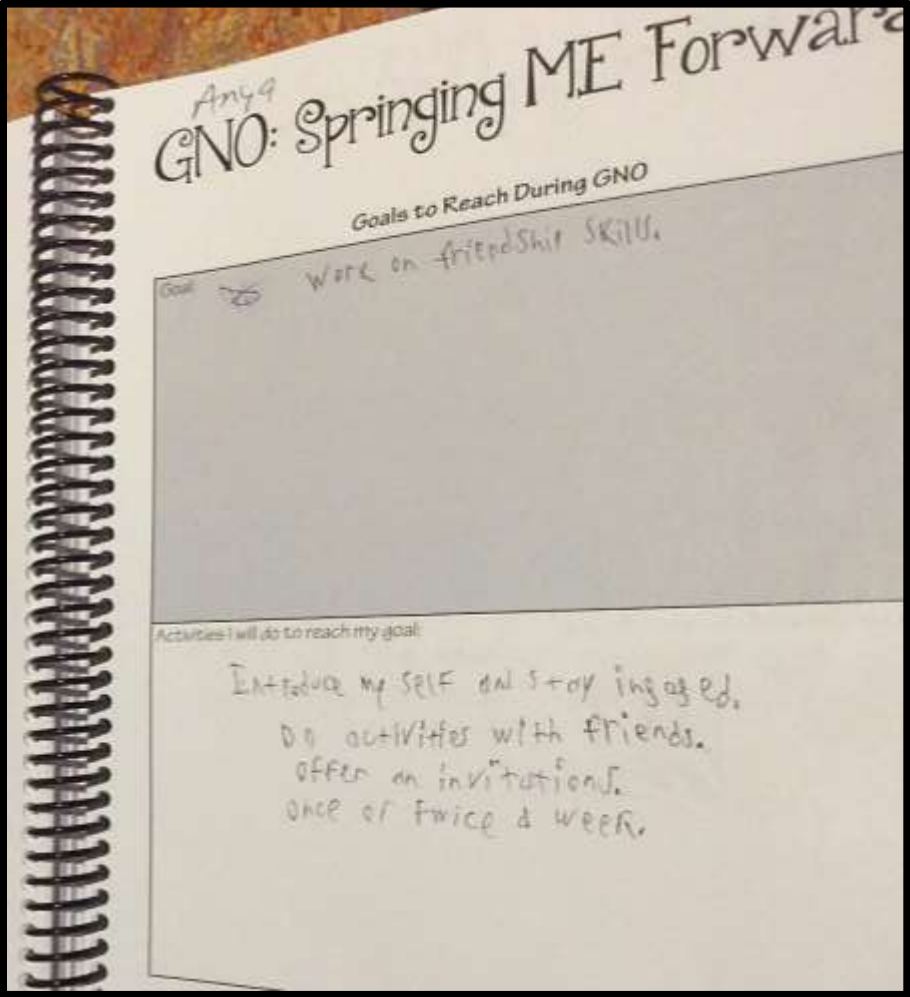


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GNO: Springing ME Forward

Goals to Reach During GNO

Goal:



Work on friendship skills.

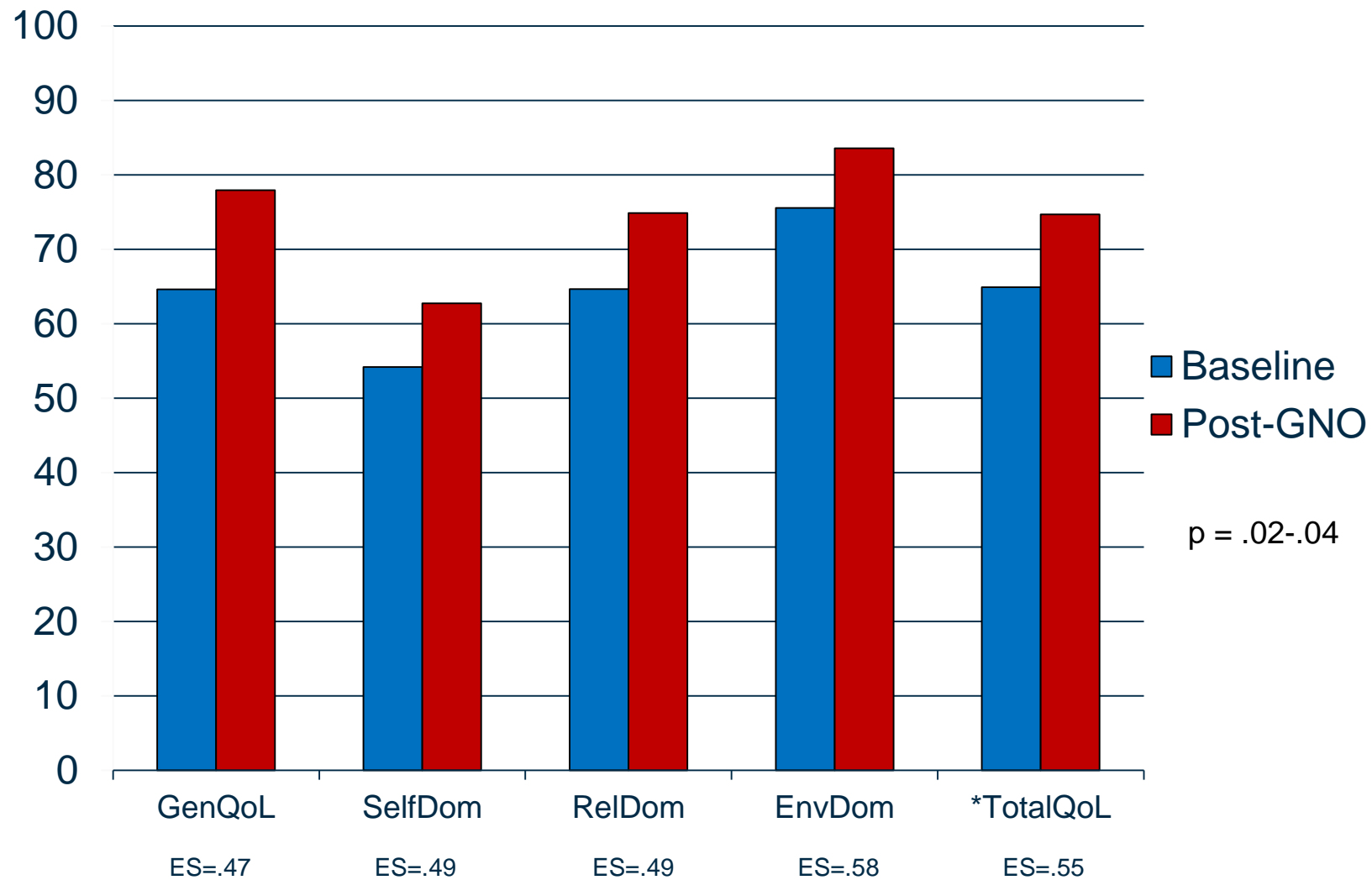
Activities I will do to reach my goal:

Introduce my self and stay engaged.
Do activities with friends.
offer an invitations.
once or twice a week.

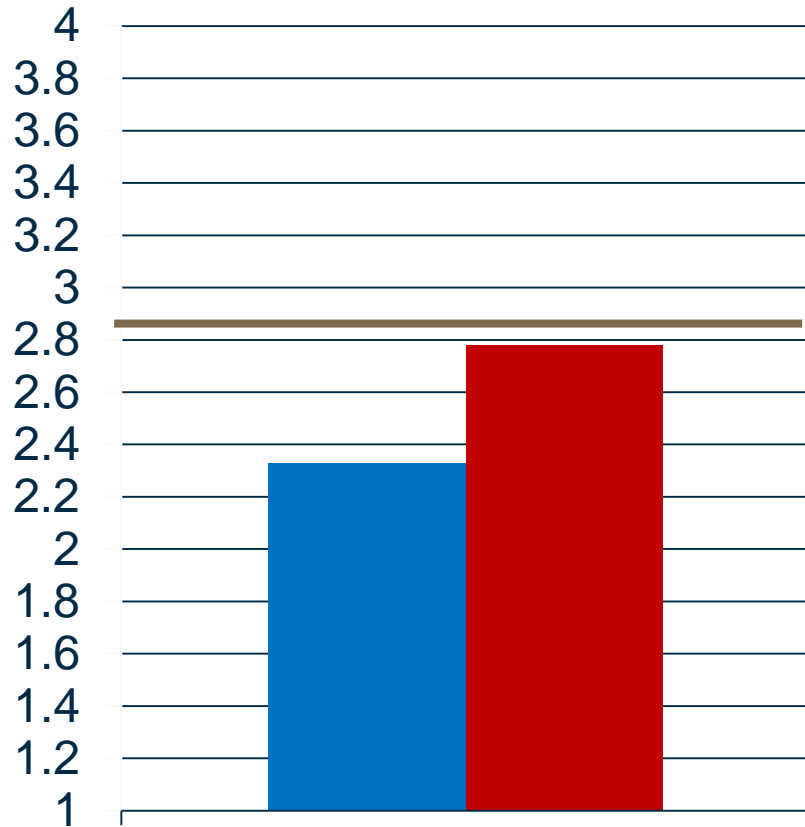
PROGRAM EVALUATION OUTCOMES



Figure 3: YQOL-R Subscale and Total Scores

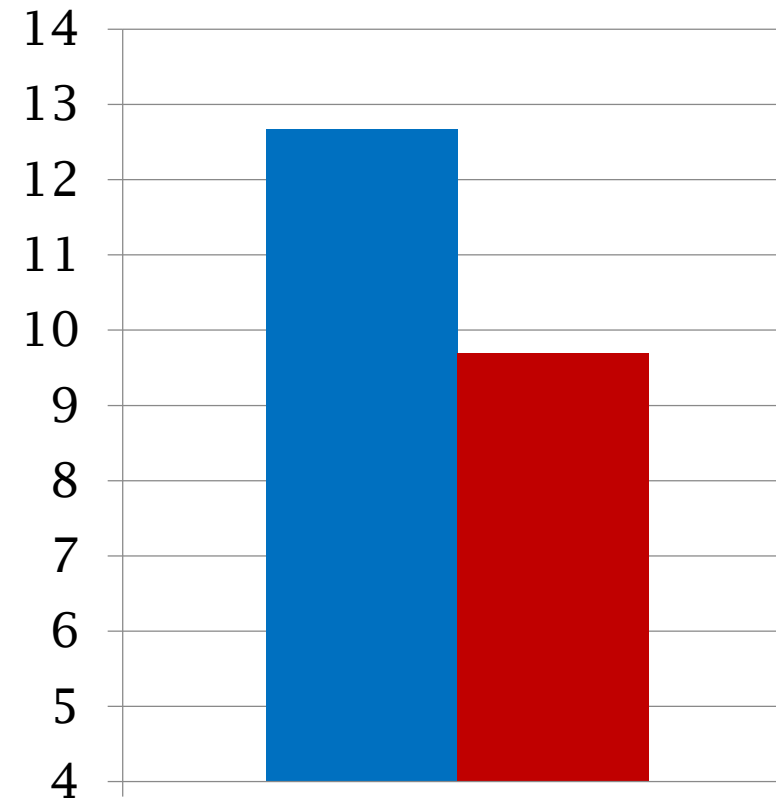


PERCEIVED SOCIAL-EMOTIONAL HEALTH



Global Self-worth

$p < .05$; $d = .53$

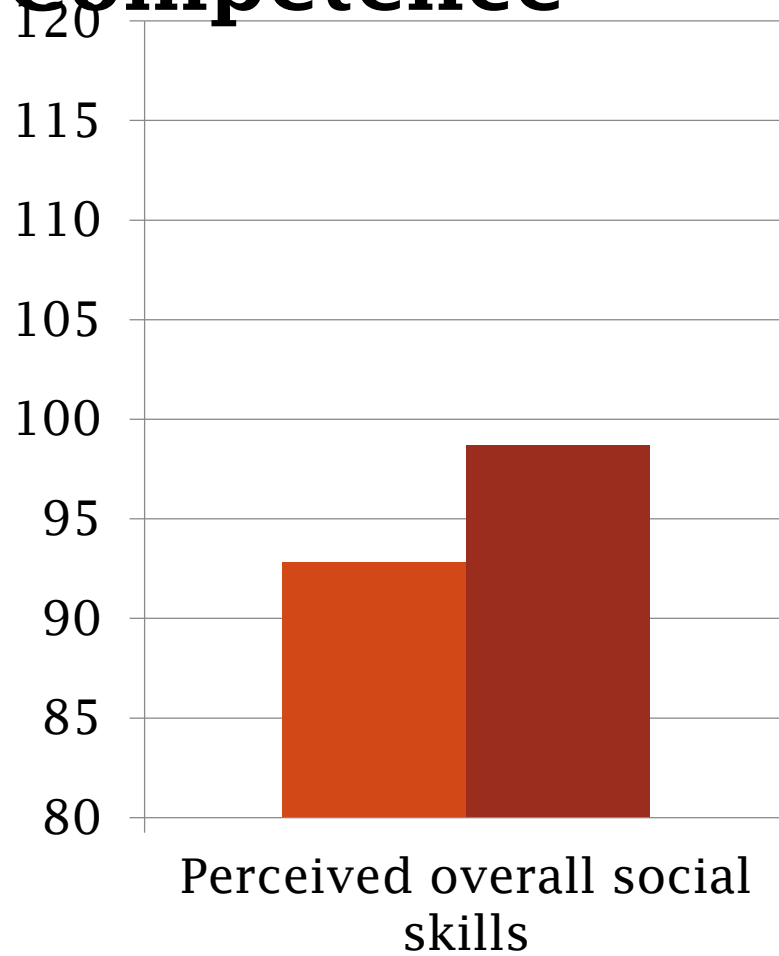


Internalizing Symptoms
(anxiety, depression)

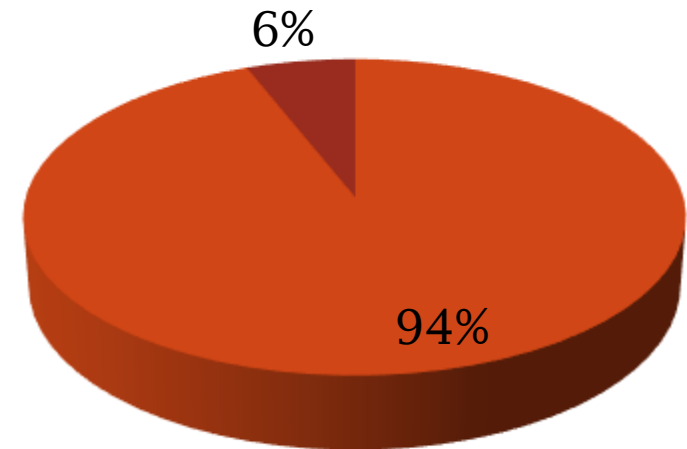
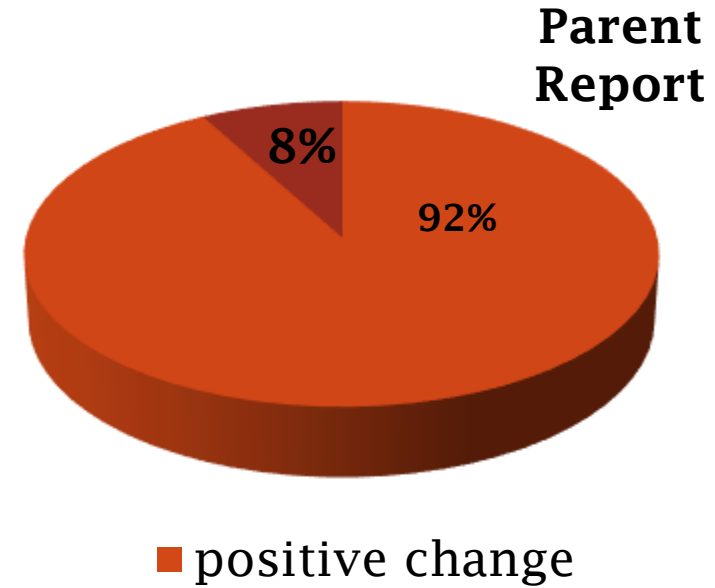
$p < .003$; $d = .45$



Social Competence



$p < .011$; $d = .43$



Participant Report



The Impact So

Far.

"These girls nights just keep getting better & better"

"We need GNO for 10 years at least!"



"....it made me get more interaction with people and get out of my comfort zone"

"I almost did not sign her up because of the cost...but it was the best money I've spent on her IN YEARS!"

"this girls night out is the most fun I've ever had."



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Parents Night Out
(PNO)

COMMUNITY
EVENTS

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“GNO
Alumni”



EXPANDING PROGRAMS: GNO-JR



My daughter finally
gets to be in GNO!!!
Peer volunteer GNO-
JR

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Pilot skills group: April
2018

GNO-JR: Girls 10-13 years old



COMMUNITY WIDE

14 GNO Skills
Groups (168
Sessions)

+

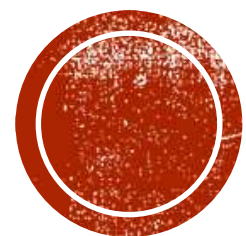
18 Community
Events

More than **38** trained
facilitators (medical
students, graduate
students, fellows,
community volunteers)

Over **65** Community
Partners

Including over **100**
girls with autism
and 125 peer
volunteers!!!

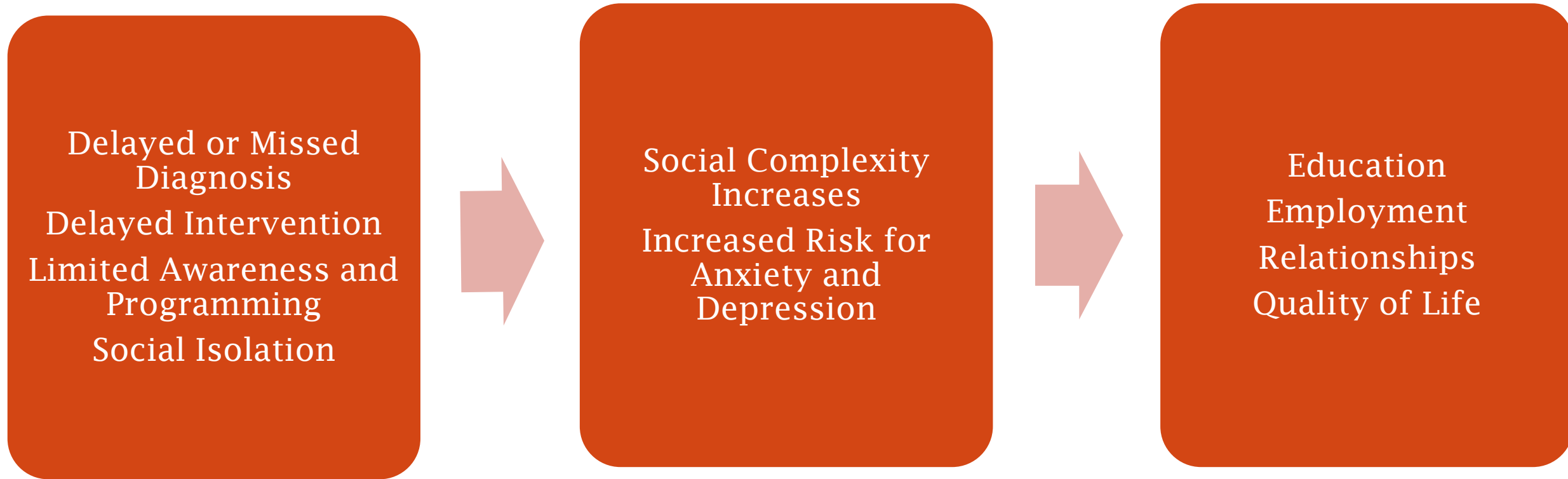




THERE'S MUCH MORE WORK TO BE DONE

The Vision for responsive and anticipatory supports and services, across the lifespan, and impacting the broader community.

Trajectory for Females with ASD



But what if....we could *change the trajectory*?



Delayed or Missed
Diagnosis
Delayed
Intervention
Limited Awareness
and Programming
Social Isolation



Social Complexity
Increases
Increased Risk for
Anxiety and
Depression



Education
Employment
Relationships
Quality of Life

But what
if....we
could
*change the
trajectory?*

Knowledge &
Understanding

More accurate
diagnosis
Better
intervention
Peer Pool

Build Skills & Supports

Build social
networks
More socially
valid
interventions
Anticipating &
Preventing

Enhance Protective
Factors

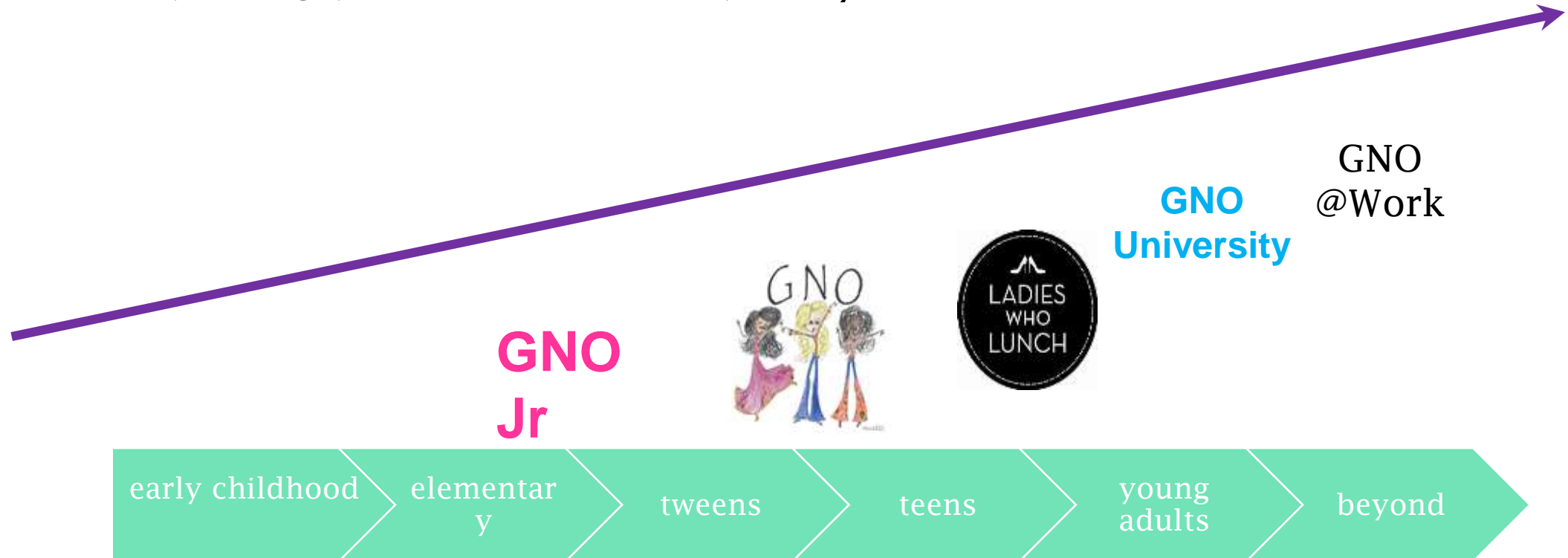
Ongoing
Networks and
Opportunities
Social
Competence
Positive Self
Concept



A New Direction....

RESPONSIVE PROGRAMMING ACROSS THE LIFESPAN

- Anticipating developmental changes and ways to intervene at key timepoints
- GNO Teen, GNO Jr, Ladies Who Lunch, & Beyond...



Programs & Supports Across the Lifespan



Connecting Families, Creating On-Going Social Opportunities, and Providing Expanded Supports



Meaningful and Sustainable Impact.....Changing the Course!

The Most
Powerful
Outcome

PHOTO WAS
HERE
(best friends and
college
roommates that
met in GNO)



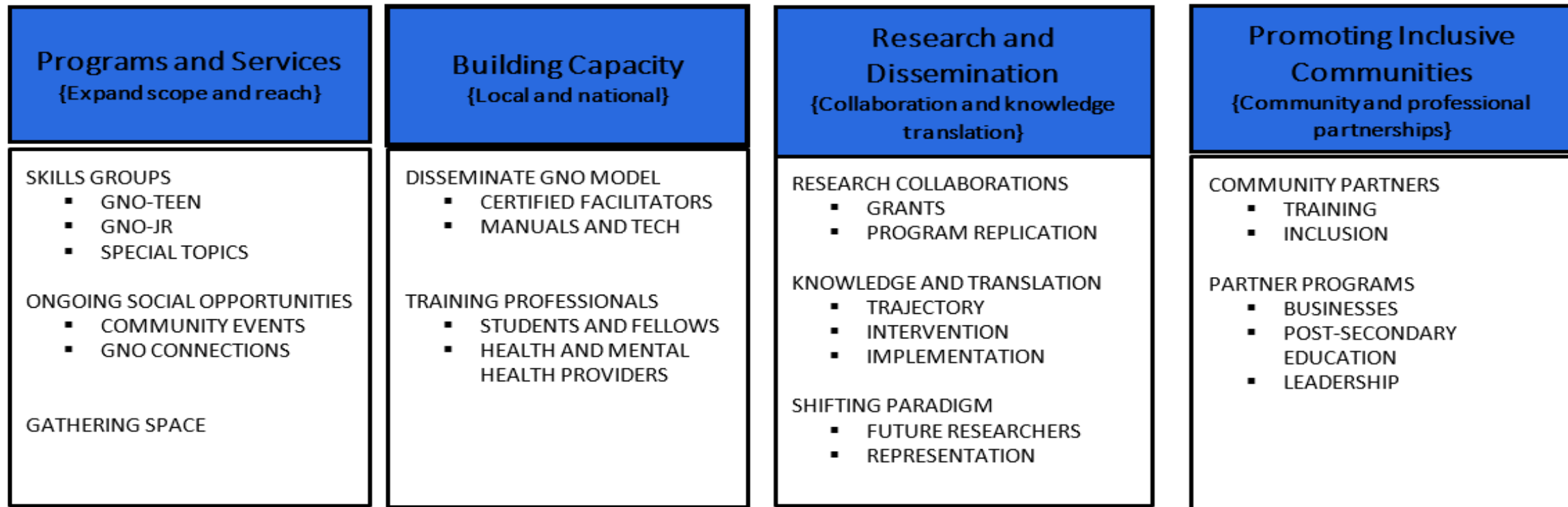
SUSTAIN & EXPAND ACCESS

TRAINING & DISSEMINATION
OF BEST PRACTICES

ENHANCE INCLUSIVE
PRACTICES



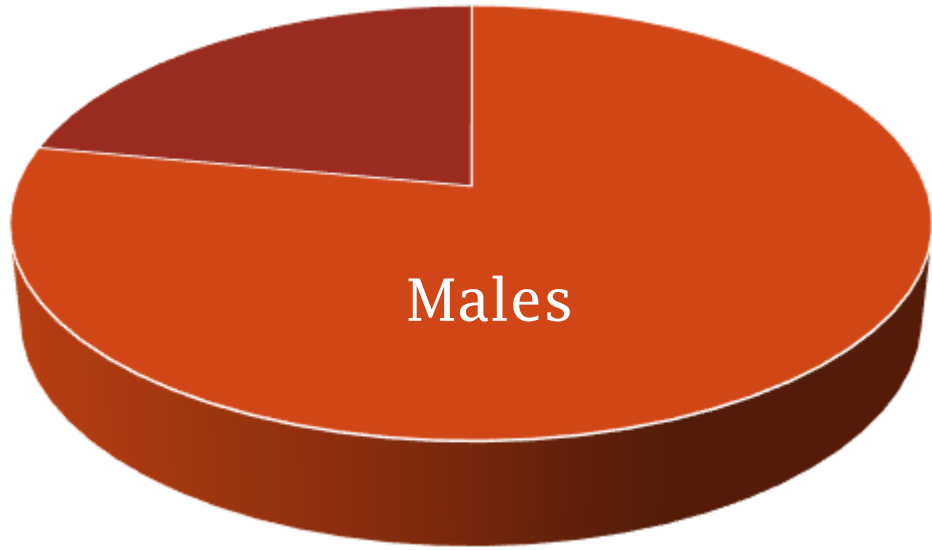
GNO Program Model



Increased access to and enhanced quality of social-emotional supports and services for girls and women with ASD/NDD, results in improved social-emotional health for women and girls with ASD and engagement and contribution to their community.



Take home message and challenge



Influence the pie!

- Consider female presentation
- Evaluate your practice
- Tell your friends!

Consider implications and



APPRECIATION & THANK YOU!

- Participants
- Families
- Facilitators
- Community Partners
- Peer volunteers
- Donors
- CCHD
- GNO Rock Stars
 - Jessica Schuttler
 - Miranda Gilmore
 - Malloreay Marek
 - Diane Guthrie



and my
family.....Juliana,
Vincent, & Dustin



QUESTIONS?? COMMENTS???

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