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
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
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 $\rightarrow$ decreased focus $\rightarrow$ "female

Frazier, et al 2014
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).
<table>
<thead>
<tr>
<th>Demographics</th>
<th>N (%)</th>
<th>Mean age (range)</th>
<th>Co-existing Internalizing</th>
<th>Co-existing Externalizing</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Females</strong></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>255 (100%)</td>
<td>6.43 (1-20)</td>
<td>14 (5%)</td>
<td>77 (30%)</td>
</tr>
<tr>
<td>ASD</td>
<td>115 (45%)</td>
<td>6.03* (1-20)</td>
<td>3 (3%)</td>
<td>21 (20%)</td>
</tr>
<tr>
<td>No ASD</td>
<td>140 (55%)</td>
<td>6.75 (1-18)</td>
<td>11 (9%)*</td>
<td>56 (46%)*</td>
</tr>
<tr>
<td><strong>Males</strong></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>1021 (100%)</td>
<td>6.10 (0-21)</td>
<td>55 (5%)</td>
<td>432 (42%)</td>
</tr>
<tr>
<td>ASD</td>
<td>532 (52%)*</td>
<td>6.03* (1-21)</td>
<td>29 (6%)</td>
<td>158 (30%)</td>
</tr>
<tr>
<td>No ASD</td>
<td>489 (48%)*</td>
<td>6.18 (0-18)</td>
<td>26 (5%)</td>
<td>274 (56%)*</td>
</tr>
<tr>
<td><strong>Total Sample</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>1276 (100%)</td>
<td>6.17 (0-21)</td>
<td>69 (5%)</td>
<td>509 (40%)</td>
</tr>
<tr>
<td>ASD</td>
<td>647 (51%)</td>
<td>6.03 (1-21)</td>
<td>32 (5%)</td>
<td>179 (28%)</td>
</tr>
<tr>
<td>No ASD</td>
<td>629 (49%)</td>
<td>6.30 (0-18)</td>
<td>37 (6%)</td>
<td>330 (52%)</td>
</tr>
</tbody>
</table>
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 & Tchanturua, 2015; Lai et al., 2011; Lai et al., 2015; National Autistic Society ‘Autism in Pink’ project
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

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

Earlier pretend & imaginative play

Empathy

Conversational skills

Sex differences in social-communication
Increased social difficulties and risk for anxiety and depression
Individuals with autism scores below that of those without ASD

Girls with autism scored similar to boys WITHOUT autism.

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

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?

<table>
<thead>
<tr>
<th>Participant Type</th>
<th>Focus Groups</th>
<th>Total Number</th>
<th>Mean Age (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adolescent Females with Autism</td>
<td>4*</td>
<td>14</td>
<td>15.57 (1.22)</td>
</tr>
<tr>
<td>Adolescent Girls without Autism</td>
<td>4</td>
<td>20</td>
<td>15.85 (1.30)</td>
</tr>
<tr>
<td>Parents of Girls with Autism</td>
<td>4*</td>
<td>15</td>
<td>NA</td>
</tr>
<tr>
<td>Parents of Girls without Autism</td>
<td>2</td>
<td>12</td>
<td>NA</td>
</tr>
</tbody>
</table>

Schuttler et al., manuscript in progress
<table>
<thead>
<tr>
<th>Themes</th>
<th>Supporting Quotes</th>
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<tbody>
<tr>
<td><strong>Limited Social Opportunities and Interactions</strong></td>
<td>“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)</td>
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<td>“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)</td>
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<td>“I’d say she has online friends, that’s it. She likes to...yeah, that she plays games with and...Virtual friends.” (PA)</td>
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<tr>
<td><strong>Planning &amp; Coordination Shift</strong></td>
<td>“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 what's happening next you stay in the &quot;group&quot; and in the &quot;loop.&quot; (NA)</td>
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<td>“…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)</td>
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<td>“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)</td>
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<td>“She wouldn’t invite the kids, but she would direct me to organize with the parents.” (PA)</td>
</tr>
<tr>
<td><strong>Increased Complexity</strong></td>
<td>“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)</td>
</tr>
</tbody>
</table>
Ascertainment bias

Males
Ascertainment bias

IV Generalizability?
Ascertainment bias
Limited peer pool
Males
IV Generalizability?
Ascertainment bias

Limited peer pool

Gender nuanced skills

IV Generalizability?
Exacerbated social communication challenges, heightened risk for internalizing symptoms.

- Limited peer pool
- Gender nuanced skills
- IV Generalizability?
- Ascertainment bias

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

Jamison & Schuttler, 2015

DOI 10.1186/s12323-015-0043-a

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
Adolescence

Female

Autism

Increased social difficulties and risk for anxiety and depression

A unique intervention to address complex needs of adolescent girls with autism
Overview and Preliminary Evidence for a Social Skills and Self-Care Curriculum for Adolescent Females with Autism: The Girls Night Out Model

T. Rene Jamison · Jessica Oeth Schultler
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!!!!!
PROGRAM STRUCTURE

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

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

Core curriculum components

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

PHOTO WAS HERE

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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
<table>
<thead>
<tr>
<th>Social Learning Theory (SLT)</th>
<th>Cognitive-Behavioral Theories (CBT)</th>
<th>Behavioral Theories (BT)</th>
</tr>
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<tbody>
<tr>
<td><strong>Peer Mediated</strong>&lt;br&gt;Pt: Social Learning Theory [SLT]</td>
<td>Behaviors and new skills are learned through observation of others (Bandura, 1971)</td>
<td>Behaviors and skills learned by understanding emotional and cognitive interpretations of events, with cognitive and behavioral rehearsal of appropriate behaviors (Kendall, 2006).</td>
</tr>
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<td><strong>Video Modeling (VM)</strong></td>
<td>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, &amp; Scahill, 2007).</td>
<td>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, &amp; Levinson, 2002).</td>
</tr>
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<td><strong>Modeling &amp; Role Play</strong></td>
<td>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).</td>
<td>Using differential attention (Pemberton, Borrego, &amp; Sherman, 2013) with some prompting to encourage desired behaviors, followed by specific praise for engaging in desirable behaviors.</td>
</tr>
<tr>
<td><strong>Visual Supports</strong></td>
<td>Facilitator or peer demonstration of skills. Role plays include practice situations &amp; feedback on skill use. Role play may be used to teach or assess skills (Ratto, 2010).</td>
<td>Self-monitoring strategies may increase the use of numerous targeted skills among individuals with ASD (Hume Loftin, and Lantz, 2009).</td>
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<td>Tools that help individuals organize and complete activities and tasks by presenting information such as schedules, prompts or cues visually (Johnston, Nelson, Evans, &amp; Palazolo, 2003).</td>
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<td>Cognitive-Behavioral Theories (CBT)</td>
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<td>Behavioral Theories (BT)</td>
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</tr>
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<td></td>
<td>Task analysis</td>
<td>Breaking down a task into smaller, component parts that are taught and practiced individually, then combined (Franzone, 2009).</td>
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<td></td>
<td>Token Economy</td>
<td>Positive reinforcement paired with tangible reinforcers (“GNO bucks”) which can be exchanged for desired items (Atyeo and Forchuck, 2013).</td>
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<tr>
<td></td>
<td>Reinforcement of target skills</td>
<td>Positive reinforcement of desired behaviors is effective in increasing desired behaviors during social skills training. (Gresham, Sugai, &amp; Horner, 2001).</td>
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</tbody>
</table>
MEET AND GREET: SESSION ONE

Overview and the “Stuff” we use in GNO

Outline
Peer training
Step in or stand up
The stuff
“what brought you to the conference?”

“Have you ever been to this conference before?”

“What kind of work do 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

Person
Finding out about someone

Activity
Talking about where you are at & what you are doing

Relationship
Common ground, compliments, emotional support.

Video model: Finding out about friends.
Peer Training
PROMOTING INDEPENDENCE IN SELF-CARE SKILLS

- Clothing selection
- Body care (hygiene)
- Skin care
- Hair care
- Health (fitness, nutrition)
Positive Self-concept (Confidence)

Healthy social/emotional (available for learning)

Implement skills / Engagement

Improved Social Competence
**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.

5:00-6:00  
**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 role. 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.
- Review homework and importance of contacting and going through Gabby’s getting ready prior to next session. Encourage texting and pics to GNO friends and others.

6:00-6:15  
**GNO Initial Activities & “Business”**

- Distribute GNO bucks for bringing homework, planners & W/D/TW 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).

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

- Brief overview followed by Relate to partner and activity iPad presentation in small groups
  - Blink partner up and go through Keynote presentation on iPad (content, examples, video clip)
  - Conversation practice using sayings for topic ideas.
- Data collection (questions, comments, and content type (P, A, R)) during 1 minute practice scenarios.

6:25-6:40  
**Homework & Partner Activity**

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

6:40-7:40  
**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 (14 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!
What will I wear?

What parts of my body will show?

What do I need to do to get my body ready?
**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
<table>
<thead>
<tr>
<th>Date</th>
<th>I did a club or group activity</th>
<th>Self-care activities I did on my own (or without much help)</th>
<th>I did physical activity or other exercise</th>
<th>I called/texted a friend</th>
<th>I hung out with a friend outside of school</th>
<th>Parent Reviewed (initials)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Pick out clothes, Fix hair, Makeup or skin care</td>
<td>Chat, Make Plans</td>
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</table>

Any GNO: Springing ME Forward

Goals to Reach During GNO

Goal: Work on friendship skills.

Activities I will do to reach my goal:

- Introduce myself and stay engaged.
- Do activities with friends, offer or invite activities once or twice a week.
GOAL: Springing ME Forward

Goals to Reach During GNO

Goal: Work on friendship skills.

Activities I will do to reach my goal:

- Introduce myself 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

Baseline
Post-GNO

p = .02-.04

ES=.47
ES=.49
ES=.49
ES=.58
ES=.55

GenQoL  SelfDom  RelDom  EnvDom  *TotalQoL
PERCEIVED SOCIAL-EMOTIONAL HEALTH

Global Self-worth
p < .05; d = .53

Internalizing Symptoms (anxiety, depression)
p < .003; d = .45
Social Competence

Perceived overall social skills

Parent Report

- 92% positive change
- 8%

Participant Report

- 94%
- 6%

p < .011; d = .43
The Impact So Far...

These girls nights just keep getting better & better

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

"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!"
Parents Night Out (PNO)

“GNO Alumni”

COMMUNITY EVENTS

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EXPANDING PROGRAMS: GNO-JR

GNO-JR: Girls 10-13 years old

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

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Pilot skills group: April 2018
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!!!
The Vision for responsive and anticipatory supports and services, across the lifespan, and impacting the broader community.
But what if....we could *change the trajectory*?
But what if....we could change the trajectory?

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

Delayed Diagnosis Increases
Increased Risk for Anxiety and Depression

Social Complexity Increases

Education
- Employment
- Relationships
- Quality of Life

A New Direction....

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
RESPONSIVE PROGRAMMING ACROSS THE LIFESPAN

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

The diagram illustrates a timeline from early childhood through young adults and beyond with various programs such as GNO Jr, GNO University, and GNO @Work.
Programs & Supports Across the Lifespan

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

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

PHOTO WAS HERE
(best friends and college roommates that met in GNO)
SUSTAIN & EXPAND ACCESS

TRAINING & DISSEMINATION OF BEST PRACTICES

ENHANCE INCLUSIVE PRACTICES
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
  - Mallorey Marek
  - Diane Guthrie

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