

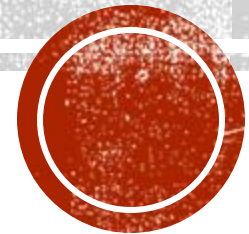
# **SEX MATTERS: THE SECONDARY IMPACT OF LOW PREVALENCE FOR GIRLS AND WOMEN WITH AUTISM**

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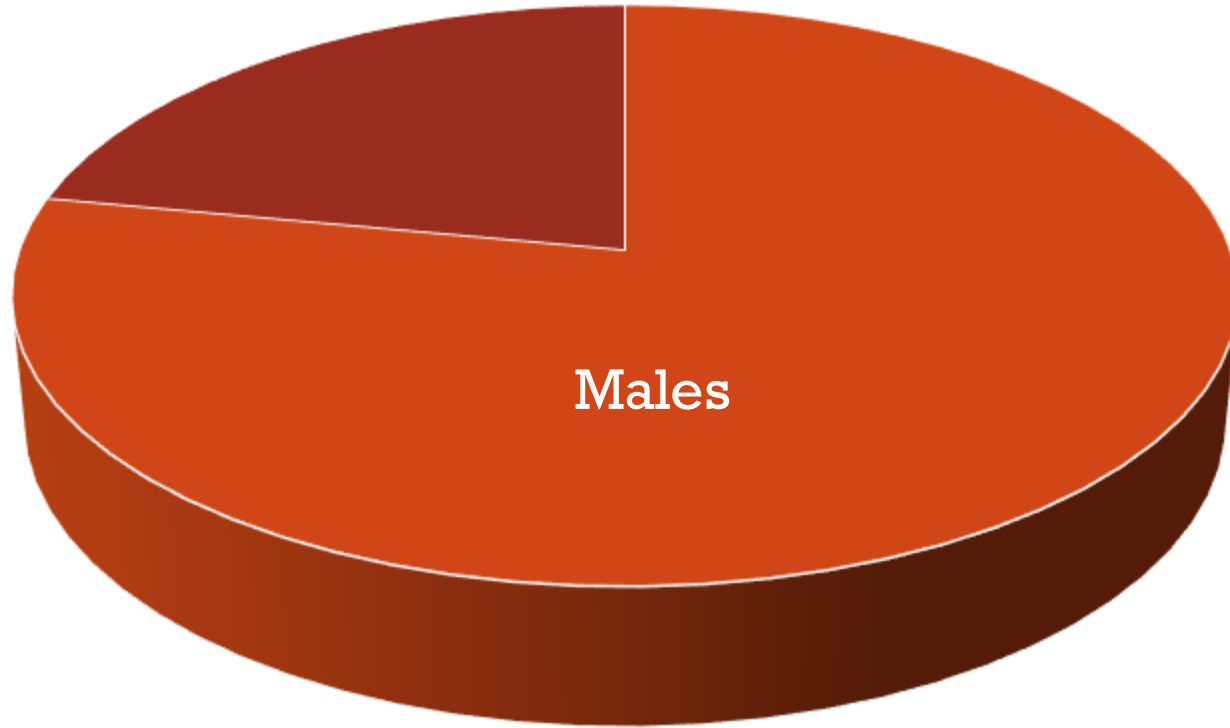


# AGENDA

- Overview of Secondary Impact
- Implications for Practice
- GNO Vision



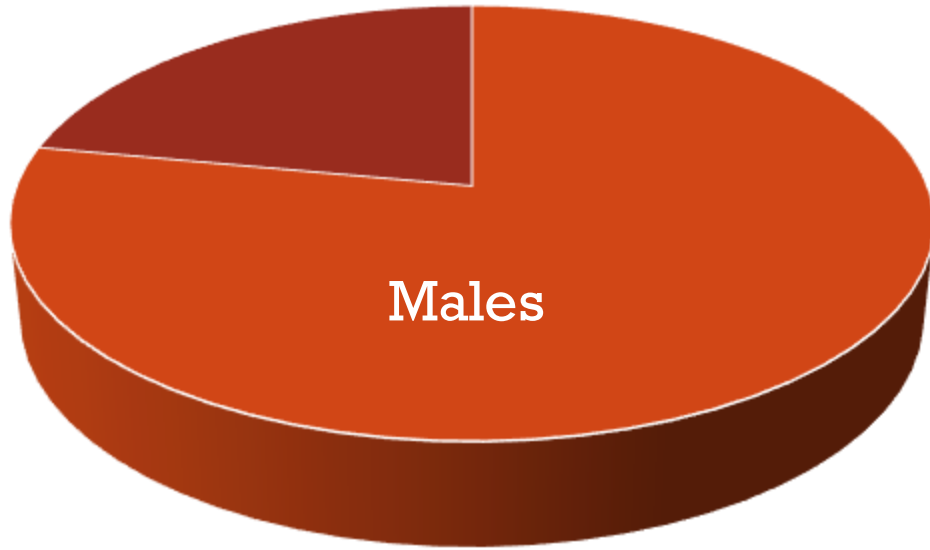
# Greater prevalence in males



4:1 – Male to Female Ratio

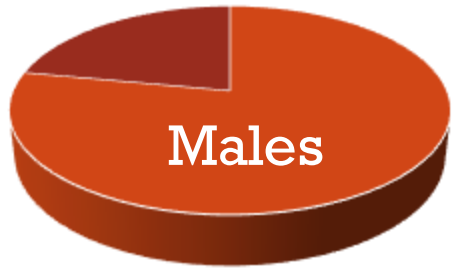


# Greater prevalence in males

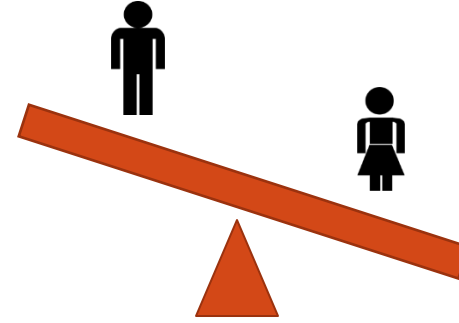


Lesser impact on females  
in general population  
→ decreased focus  
→ "female protection"

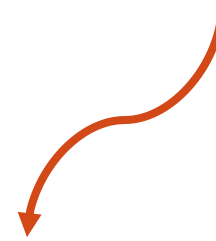




## Published Research



82% of participants in published research studies are male

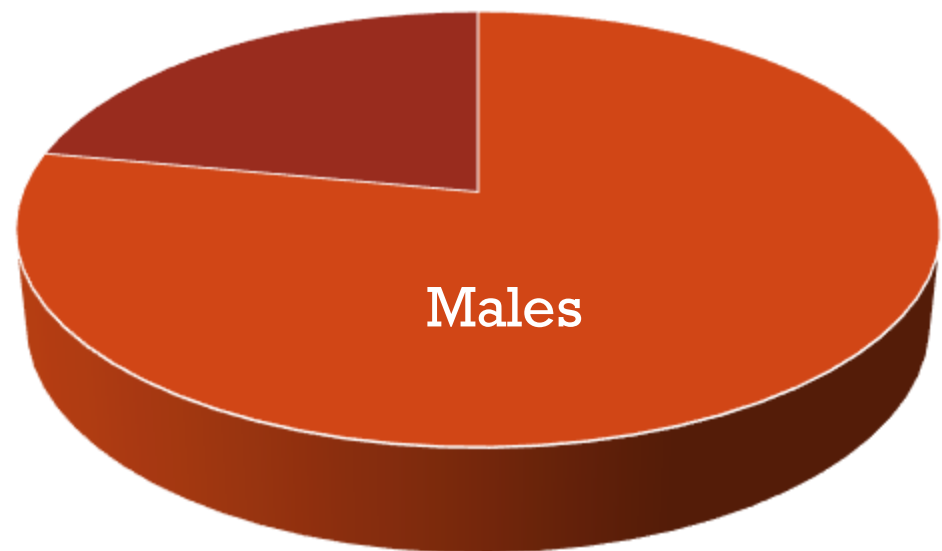


## Potential Implications

- 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



# 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?

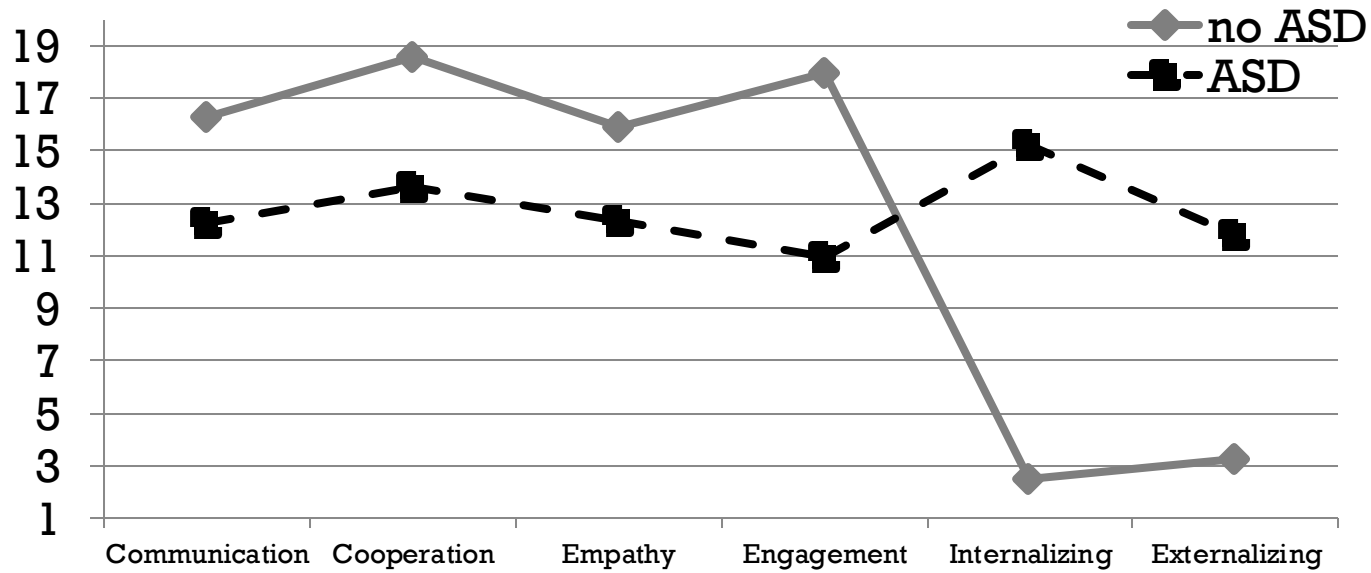
Participant Type	Focus Groups	Total Number	Mean Age (SD)
Adolescent Females with ASD	4*	14	15.57 (1.22)
Typically Developing Adolescent Girls	4	20	15.85 (1.30)
Parents of Girls with ASD	4*	15	NA
Parents of Girls without ASD	2	12	NA

Schuttler et al.,  
manuscript in progress





Themes	Example Codes	Supporting Quotes
<p><b>Limited Social Opportunities and Interactions</b></p>	<p>GASD report impact of limited social interactions with friends</p> <p>GASD report limited activities</p> <p>PASD looking for social group for GASD</p>	<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.”</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.”</p> <p>“I’d say she has online friends, that’s it. She likes to...yeah, that she plays games with and...Virtual friends.”</p> <p>“you know, her one good friend and then the two or three others that she texts with. But they’re random people, she’s never met them.</p>
<p><b>Planning &amp; Coordination</b></p>	<p>NASD report planning activities and future activities while with friends</p> <p>NASD meet friends through friends</p> <p>PASD coordinate activities</p> <p>GASD waits for initiation of plans</p>	<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."</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.”</p> <p>“and I went to great great lengths to go and get the kids in town and bring them to us.”</p> <p>“She wouldn’t invite the kids, but she would direct me to organize with the parents.”</p>
<p><b>Developing Independence</b></p>	<p>PASD concern that GASD rely on them too much</p> <p>NASD coordinate without parents</p>	<p>“mostly I am the one who calls”</p> <p>“I’ll still ask her, have you brushed your teeth.”</p>



Jamison and Schuttler *Molecular Autism* (2015) 6:53  
DOI 10.1186/s13229-015-0044-x

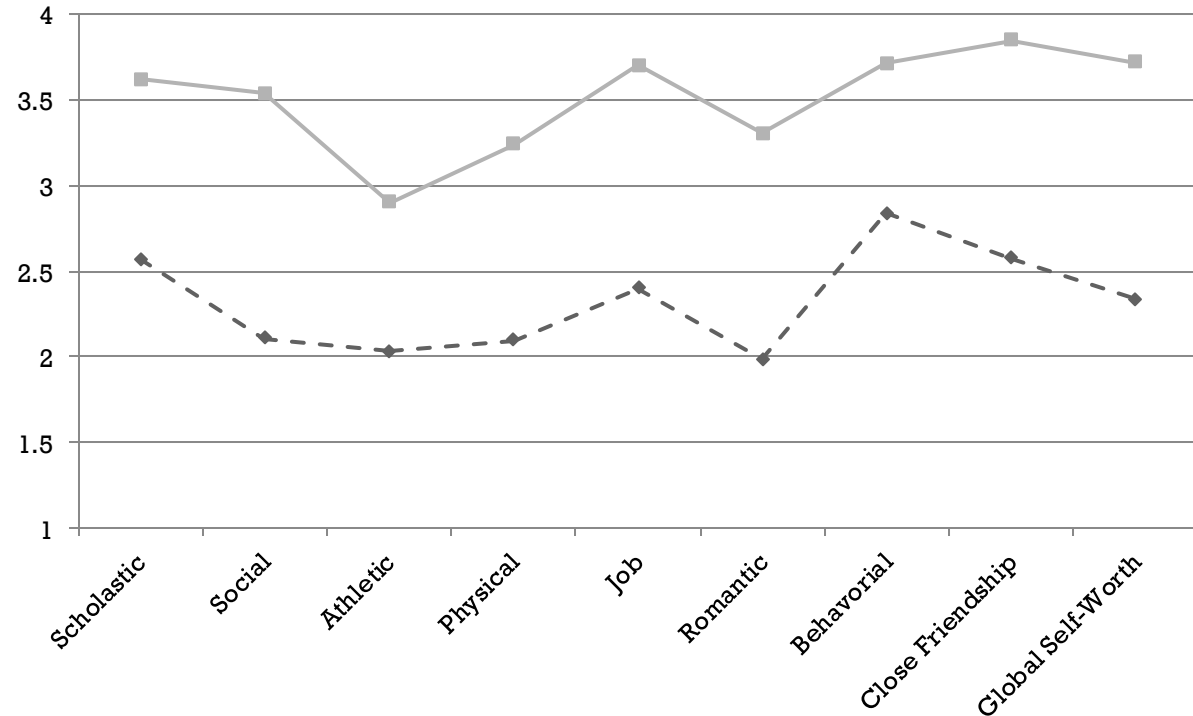


**RESEARCH** Open Access

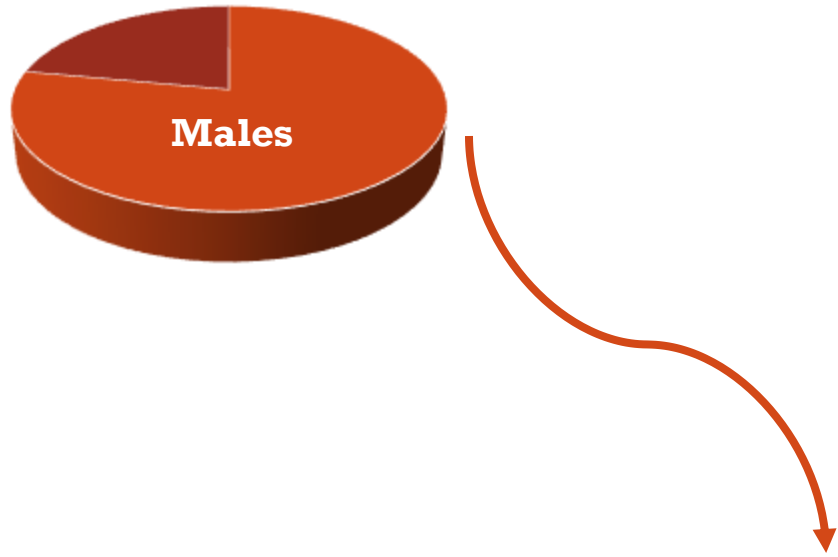
Examining social competence, self-perception, quality of life, and internalizing and externalizing symptoms in adolescent females with and without autism spectrum disorder: a quantitative design including between-groups and correlational analyses

---◇--- ASD  
---■--- No ASD

Jamison & Schuttler, 2015



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

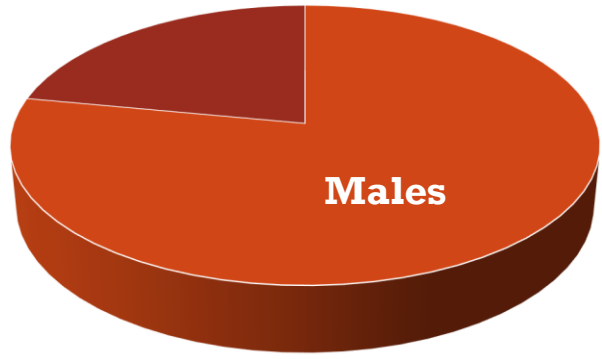


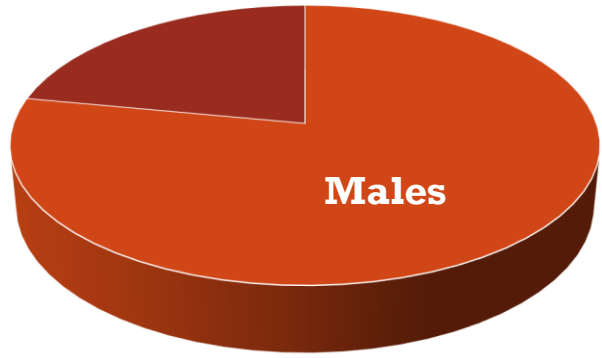
Less time spent with female peers

Limits opportunities to practice and develop gender-nuanced skills

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

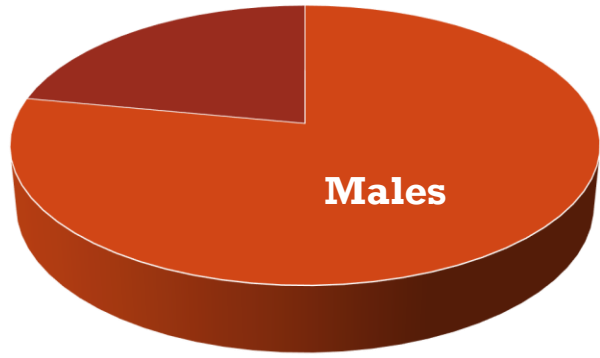






Ascertainment  
bias

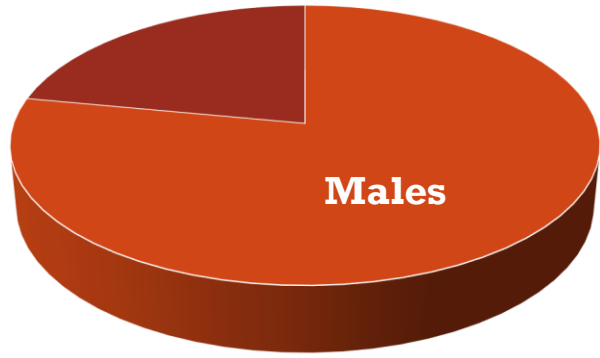




Ascertainment  
bias

IV  
Generalizability?



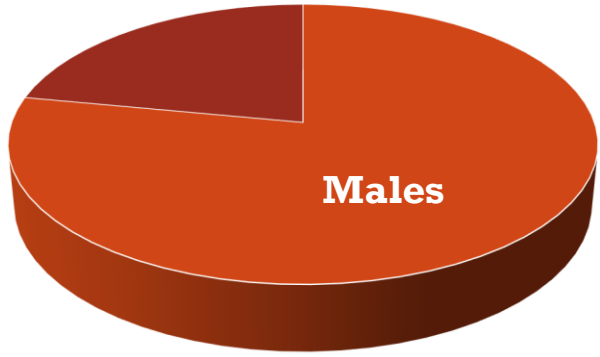


Limited peer pool

Ascertainment bias

IV  
Generalizability?





Limited peer pool

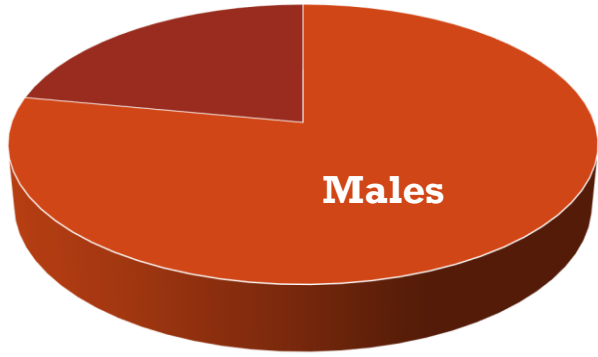
Ascertainment bias

Gender nuanced skills

IV  
Generalizability?







Limited peer pool

Ascertainment bias

Gender nuanced skills

IV  
Generalizability?

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

# CUMULATIVE IMPACT OVER TIME

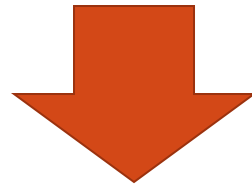
- Peer interactions become more important over time
- Shift from parent or teacher facilitated interactions towards peer initiated experiences and establishing relationships
- Increased social impairments during adolescence
- Greater risk for internalizing symptoms



# **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



# COMMUNITY WIDE IMPACT

**13** GNO Skills Groups  
(162 Sessions)

+

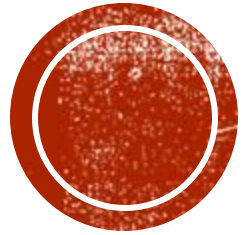
**14** Community Events

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.

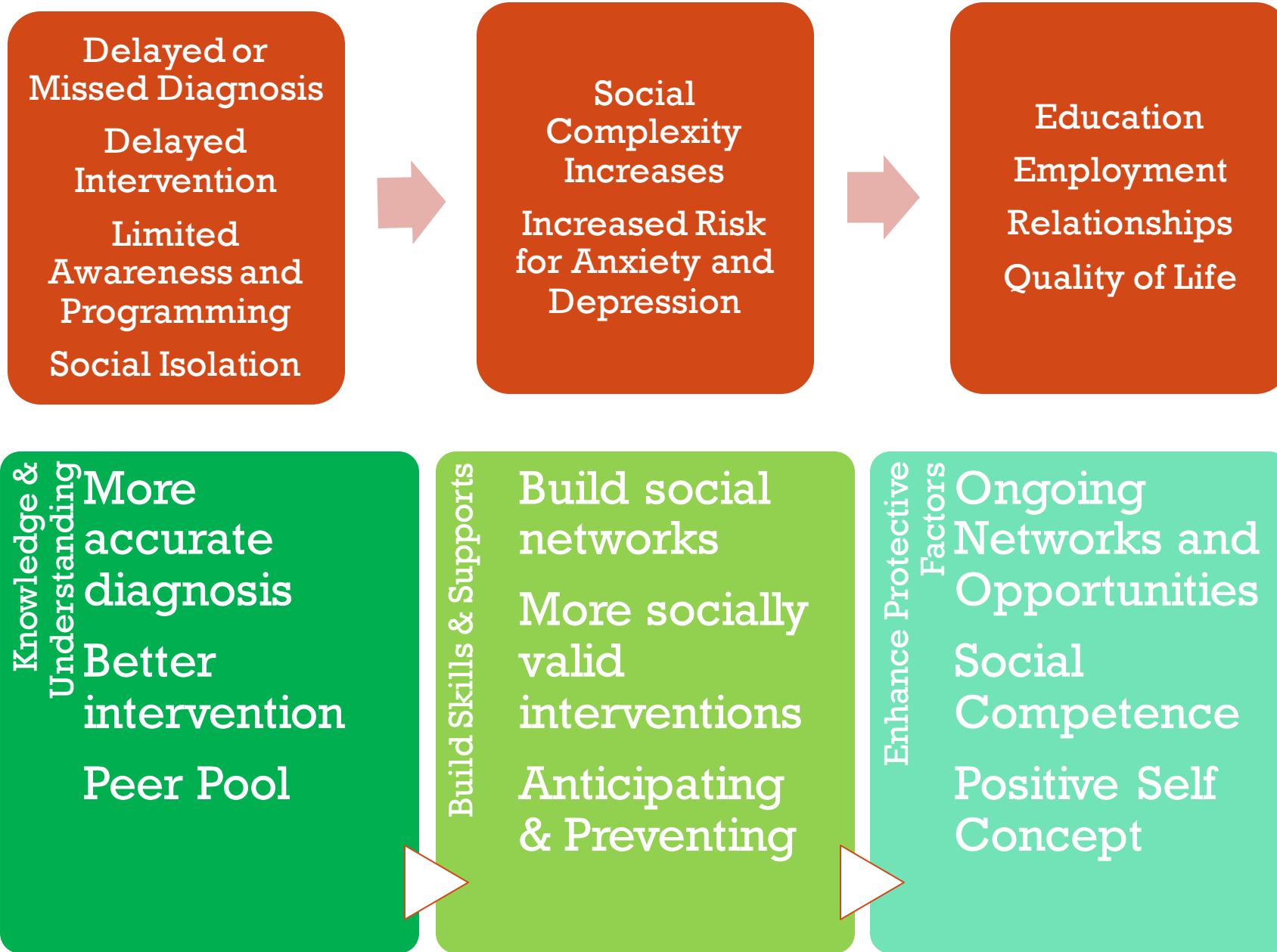
## Trajectory for Females with ASD



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



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



A New Direction....





**PURPOSE:** To improve the availability of social-emotional supports and services for girls and women with ASD/DD.

### **GUIDING PRINCIPLES**

- Females with ASD/DD have a unique profile of strengths and needs requiring responsive support practices
- Understanding needs and effective supports across the lifespan allows for preventive practices to promote social-emotional health
- People with disabilities should be fully included in their communities, with ongoing access to supportive social networks

### **PARTNERS**

- Females with ASD and their families
- Schools and community providers
- Businesses
- University and Academic Community

### **BARRIERS**

- Females with ASD/DD currently isolated within current support structures
- GNO Program begins to target specific needs, but with limited resources and structure
- Availability and scope of services does not match demand or comprehensively address needs
- Lack of knowledge/understanding of unique needs and supports of females with ASD/DD within broader community

### **STRATEGIES**

- Sustain & Expand Access to Existing Programming
- Develop Programming Responsive to Needs Across the Lifespan
- Provide Training and Dissemination for Best-Practices Programming
- Enhance Inclusive Community Partner Practices

### **SHORT TERM OUTCOMES**

- Increased social competence and opportunities for girls and women with ASD/DD
- Dedicated staff and space to support and sustain GNO program operations
- More frequent and wider ranging programming and increased access
- Increased number of organizations trained to implement GNO programming
- More frequent communication and collaboration with Community Partners

### **LONG TERM OUTCOMES**

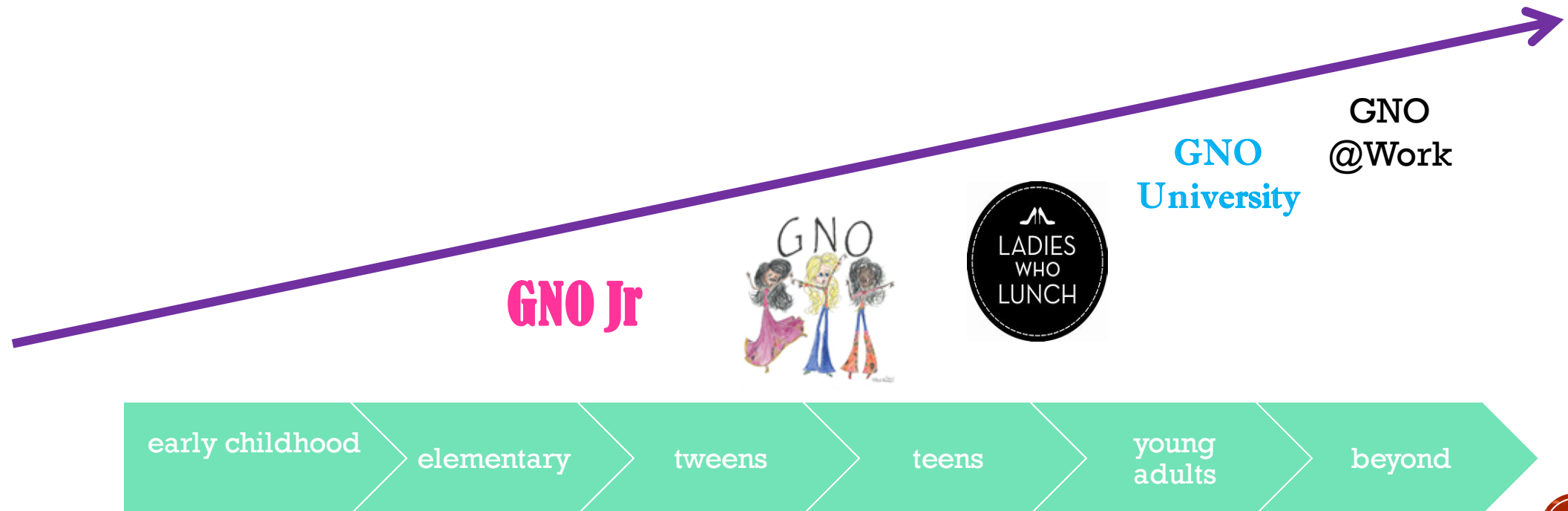
- Improved social-emotional health for women with ASD/DD
- Improved supports for women and girls with ASD
- More inclusive communities

**ULTIMATE IMPACT:** Increased and enhanced social-emotional and environmental supports will improve social-emotional health for women and girls with ASD and enhance their ability to engage with and contribute to their community.



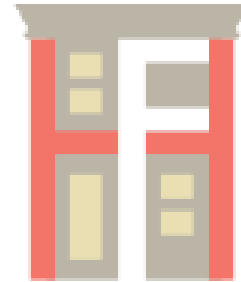
# RESPONSIVE PROGRAMMING ACROSS THE LIFESPAN

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



# SUSTAIN & EXPAND ACCESS

- Billable program structures for supports and interventions
- Ongoing program cycle
- Felicity House Model

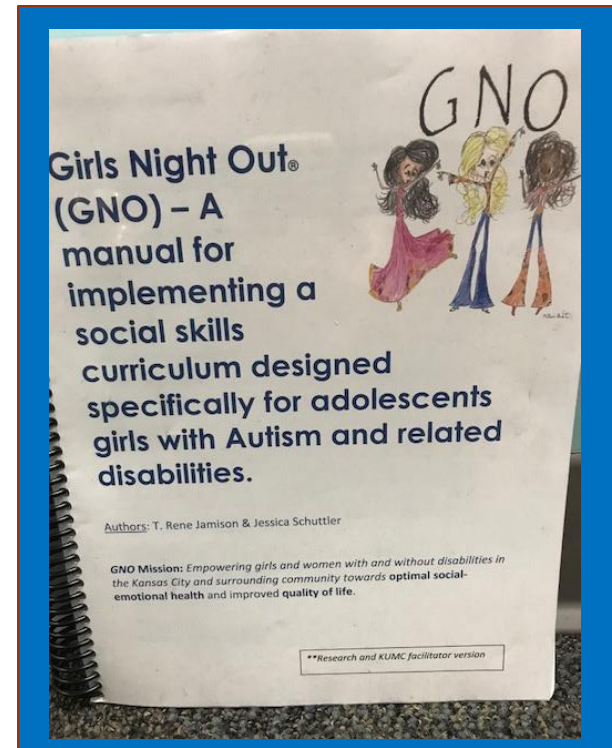


FELICITY  
HOUSE



# TRAINING & DISSEMINATION OF BEST PRACTICES

- Manual
- Trainings to Implement GNO Programming Across the Country (& Continent)



# ENHANCE INCLUSIVE PRACTICES

- Community & Corporate Partnerships
- Build Provider Capacity
- Raising Awareness and Accessibility

