



# AIR-P LEND Seminar Series: Gender, Sexuality, Reproductive Health

**Purpose**: This document corresponds with the Gender, Sexuality, Reproductive Health video in the AIR-P LEND Seminar Series. It outlines the video's content and provides suggestions on how to use this resource.

Research Node: Gender, Sexuality, and Reproductive Health

**Summary**: This video provides a foundational understanding of the AIR-P node on Gender, Sexuality and Reproductive health. An introductory presentation and panel discussion explore topics of Research gaps and sensitive topics for this node related to Gender, Sexuality, and Reproductive Health. Attendees will learn from researchers, caregivers, and advocates who will share their expertise and resources.

## Learning objectives:

- 1. Sexuality and gender in autism different expressions of sexuality, including asexuality, romance, gender identity/expression.
- 2. Autonomy and agency in sexuality and gender identity among autistic people across the lifespan
- Issues of consent and sexual abuse/assault prevention in the context of exploring intimacy

#### Outline:

| Section of<br>Video | Content Outline & Talking Points                    | Presenter(s)                        | Time allotted* |
|---------------------|---|-------------------------------------|----------------|
| General             | 1. Welcome  | Presenter (Node Leader):            | 2-5 min        |
| Overview            | 2. Context  |                                     |                |
|                     | a. Give context on AIR-P.                           | Lisa Croen, PhD                     |                |
|                     | i. <u>Autism Intervention Research</u>              | Research Scientist III, Division of |                |
|                     | Network on Physical Health   AIR-P                  | Research, Kaiser Permanente         |                |
|                     | Network (ucla.edu)                                  | Northern California; Director,      |                |
|                     | ii. Network of researchers                          | Autism Research Program, Kaiser     |                |
|                     | 3. Overview of Node                                 | Permanente Northern California      |                |
|                     | a. Describe the research node area (i.e., things to |                                     |                |
|                     | know about genetics as it related to the            | Maria Massolo, PhD                  |                |
|                     | autistic community)                                 | Practice Leader Consulting,         |                |
|                     | b. Keep target audience in mind (LEND trainees      | Kaiser Permanente Division of       |                |
|                     | with varying expertise). Research gaps can          | Research; Sr. Manager, Autism       |                |
|                     | only be understood in context of general            | Research                            |                |
|                     |   |                                     |                |





|                  | overview of node area and impact on lived   |       |
|------------------|---|-------|
|                  | experience.   |       |
|                  | 4. Learning objectives  |       |
| How is AIR-P     | 1. Dial in more specifically to research nodes' efforts to Presenter (Node Leader): 3-5                             | 5 min |
| addressing       | address the gaps in this area   |       |
| research gaps in | 2. Our node recognizes that sexuality and relationships Lisa Croen, PhD   |       |
| this node?       | are important contributors to life satisfaction, health, Research Scientist III, Division of                        |       |
|                  | and well-being. Research, Kaiser Permanente   |       |
|                  | a. <b>The node's goal is to</b> improve sexual and Northern California; Director,                                   |       |
|                  | reproductive healthcare and outcomes for autistic people across the lifespan, with a Permanente Northern California |       |
|                  | autistic people across the lifespan, with a focus on autistic women and LGBTQIA+                                    |       |
|                  | people. Maria Massolo, PhD  |       |
|                  | 3. Some of the node's priorities are:  Practice Leader Consulting,  |       |
|                  | a. Sexuality Education Kaiser Permanente Division of  |       |
|                  | b. Sexual and Reproductive Health Services Research; Sr. Manager, Autism  |       |
|                  | c. Sexual Victimization and Abuse Research  |       |
|                  | d. LGBTQIA+ Health  |       |
|                  | 4. Work guided by: participatory approach- of "nothing  |       |
|                  | about us, without us"   |       |
|                  | a. We adhere to the principles of Participatory   |       |
|                  | Based Community Research. 9-member  |       |
|                  | Advisory Group  b. They bring to our node their lived experiences,  |       |
|                  | and their academic and advocacy expertise   |       |
|                  | c. They are <b>compensated</b> for their work   |       |
|                  | d. They have found opportunities to collaborate   |       |
|                  | in research studies   |       |
|                  | 5. Collaborations   |       |
|                  | a. Workforce development- Workforce   |       |
|                  | development (clinicians, researchers,   |       |
|                  | advocates, parents, service providers)  |       |
|                  | Mentoring Early career investigators. Two   |       |
|                  | studies looking at health services utilization  |       |
|                  | among autistic adults' Ames is a staff scientist  |       |
|                  | at the Division of Research, Kaiser Permanente  Northern California. Little research on                             |       |
|                  | pregnancy in autistic people, including   |       |
|                  | obstetric risks and quality of prenatal care. Dr.   |       |
|                  | Ames study is looking at OB/GYN utilization of  |       |
|                  | autistic people, people with other  |       |
|                  | developmental disabilities and people without   |       |
|                  | autism or other developmental disabilities'   |       |





|                     | Graham Holmes is an assistant professor at the Silberman School of Social Work, Hunter College, City Univ of NY, A substantial proportion of autistic adolescents and adults are Sexual Gender Minorities, and they face unique health challenges. Study looking at SGM patterns of service utilization compared to non- SGM. Lauren Baczewski is a doctoral student at UCLA. LGBTQ+ autistic-identifying adults experience substantial disparities in access to adequate healthcare compared to their non-LGBTQ+ autistic peers. Study is trying to understand the mental healthcare experiences of autistic LGBTQ+ young adults (ages 18-26 years old). All 3 studies include autistic collaborators in data analysis and interpretation.  6. Identification of knowledge gaps- Literature Review: To identify research gaps, extensive literature review which we hope to publish later in the year. Graph illustrates the low presence in the autism literature of gender, sexuality, and reproductive health issues until the last 6 years or so. In sum: this is a new field |   |           |
|---------------------|--|---|-----------|
| Panel<br>Discussion | <ol> <li>Introductions         <ul> <li>CRE leads/co-leads and panel discussants introduce AND describe themselves (see example above).</li> </ul> </li> <li>Questions:         <ul> <li>Sexuality education is mandatory in most states in this country, and yet we have evidence that autistic youth are not receiving adequate sexuality education. In your view, who should be involved in teaching autistic youth about gender and sexuality?</li></ul></li></ol>   | Facilitator (CRE lead/co-leads): Caroline N. Coffield, PhD Director of Pre-service Training Training Director, NJLEND Assistant Professor of Pediatrics  Panel (self-advocate/lived experience, caregiver experience, professional experience/node leader):  Timotheus "T.J." Gordon, Jr. Visiting Research Associate II (Institute on Disability and Human Development at UIC) Co-Founder (Chicagoland Disabled People of Color Coalition) | 25-35 min |





- iii. Can you share a personal story what was your experience with gender and sexuality education?
- iv. What kinds of materials have you found to be helpful (ie what should LEND trainees have on hand to provide, or how can they vet materials to make sure they are neurodiversity affirming, useful, etc).
- 3. Related to this is the issues of consent, abuse/assault in the context of exploring intimacy. What's the best way to bring this up with autistic adolescents and adults? Are there resources available that address these topics? For parents/autistic individuals, including those with ID/for clinicians?
- For many parents, their child's growing awareness of their own gender and sexuality can be challenging. This may be particularly true for parents of autistic youth.
  - a. What should be the role of parents in their child's decision making about their sexuality and gender?
- 5. Closing summary

MSc in Disability and Human Development, MFA in Writing

### Lisa Croen, PhD

Research Scientist III, Division of Research, Kaiser Permanente Northern California; Director, Autism Research Program, Kaiser Permanente Northern California

#### Maria Massolo, PhD

Practice Leader Consulting, Kaiser Permanente Division of Research; Sr. Manager, Autism Research

Morenike Giwa Onaiwu an educator, writer, public speaker, parent, and global

advocate

## Tips to Use this Resource:

- Allow fellows to watch this video as homework to bring some background knowledge to a didactic seminar speaker.
- Watch together as a cohort and do a web quest for sexual health resources for those with I/DD and Autism within your State
- Have fellows watch has homework after a session and reflection on 3 changes they make now to start modeling appropriate personal boundaries and consent in their personal and professional lives.

# Sample discussion questions:

- 1. What are meaningful ways providers can model and exemplify the importance of consent and bodily autonomy?
- 2. Why do YOU think sexual education and reproductive health care are often not prioritized? What stigmas can be barriers to care that affect those with Autism?
- 3. How would you go about advocating for your patient to a caregiver, parent, or guardian when it comes to reproductive health examinations and screenings? What about after being told by the Caregiver that the individual isn't sexually active?





## **Contextual Articles:**

"As diverse as the spectrum itself". The following provides a historic and current overview of what we know about sexuality and autism with a focus on sexual and gender diversity.

https://link.springer.com/article/10.1007/s40474-020-00190-1

# Other papers/resources:

- A call to action to include youth with disabilities in sex education. This is a white paper published by Laura Graham-Holmes with SIECUS and would be useful for advocacy, which is a cornerstone of LEND:
  - https://siecus.org/wp-content/uploads/2021/03/SIECUS-2021-Youth-with-Disabilities-CTA-1.pdf
- A well-done mixed methods study on health disparities for LGBT people with autism:
  - o <a href="https://link.springer.com/article/10.1007/s10803-020-04399-2">https://link.springer.com/article/10.1007/s10803-020-04399-2</a>
- John Strang also has these community-informed clinical guidelines for gender affirming care for transgender autistic people, but focus may be too narrow (doesn't include all LGBT people):
  - o https://www.tandfonline.com/doi/full/10.1080/15374416.2016.1228462