



Autism Intervention Research  
Network on Physical Health

AIR-P Presents:

# **Addressing reproductive health and obstetrics/gynecology health care in autistic adults**

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*The data shown in this presentation is preliminary and subject to change. As such, it has been omitted from this slide deck. A recording of the full presentation can be found on YouTube or on our AIR-P website.*



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# Gender, Sexuality, and Reproductive Health Node

**Node leaders: Lisa Croen, PhD; Maria Massolo, PhD**

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**Guiding principle:** Sexuality and relationships contribute to life satisfaction, health, and well-being for all individuals

**Goal:** To improve sexual and reproductive healthcare and outcomes for autistic people across the lifespan, with a focus on autistic women and LGBTQIA+ people



# Gender, Sexuality, and Reproductive Health Node

## Proposed Node Priorities

- Sexuality Education
- Sexual and Reproductive Health Services
- Sexual Victimization and Abuse
- LGBTQIA+ Health

## Work guided by

- Stakeholder advisory group
- Identification of urgent knowledge gaps
- Workforce development (clinicians, researchers)



## A note on language:

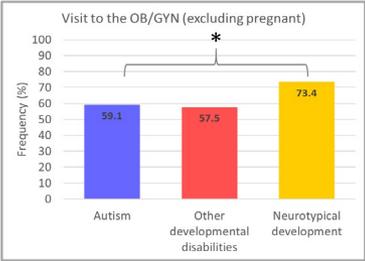


- OB/GYN services extend to people with a vulva, a vagina, or a uterus.
- We seek to use gender-neutral or gender-inclusive terms
  - gender-expansive and gender-diverse (including transgender, non-binary, agender, genderfluid, and genderqueer identities)
- Women's health or women, will be used in describing studies which focus on people who were assigned female at birth and identify as female

# Overview of presentation



Reproductive health and disability



OB/GYN Study



Data gaps and future directions



Clinical implications

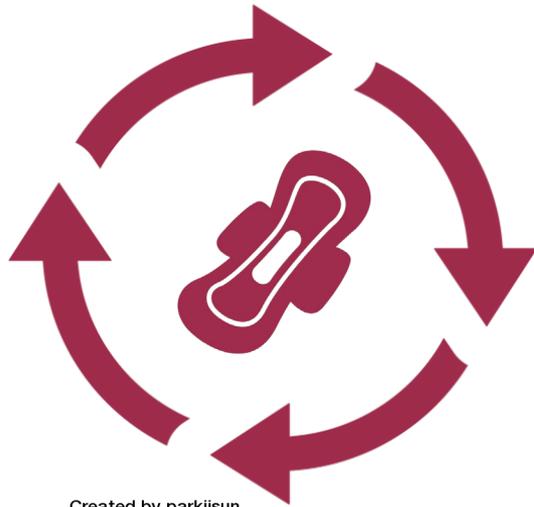
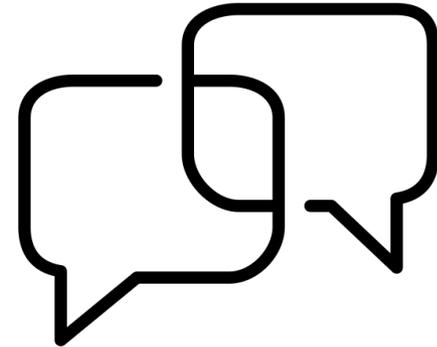
# People with disabilities often have less access to reproductive and sexual health resources than people without disabilities

- ↓ utilization of family planning services such as contraceptive counseling and use (Wu, et al. 2017; Mosher, et al. 2017; Gavin, et al. 2006)
- ↓ screening rates for breast and cervical cancer (Zerbo, et al. 2018; Smeltzer, et al. 2006; Wei, et al. 2006)
- *Few studies have focused specifically on reproductive healthcare of people with developmental disabilities such as autism*



# Autistic people face many unique challenges around reproductive health

- Social communication and sensory differences are often “invisible” to providers
- Receive fewer sexual education resources  
(Sedgewick, et al. 2018)



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- Increased risk of menstrual conditions and greater pain, sensory, and emotion/behavior problems tracking with menstrual **cycles** (Hamilton, et al. 2011; Kyrkou, et al. 2005; Obaydi, et al. 2008; Lee et al. 2004)

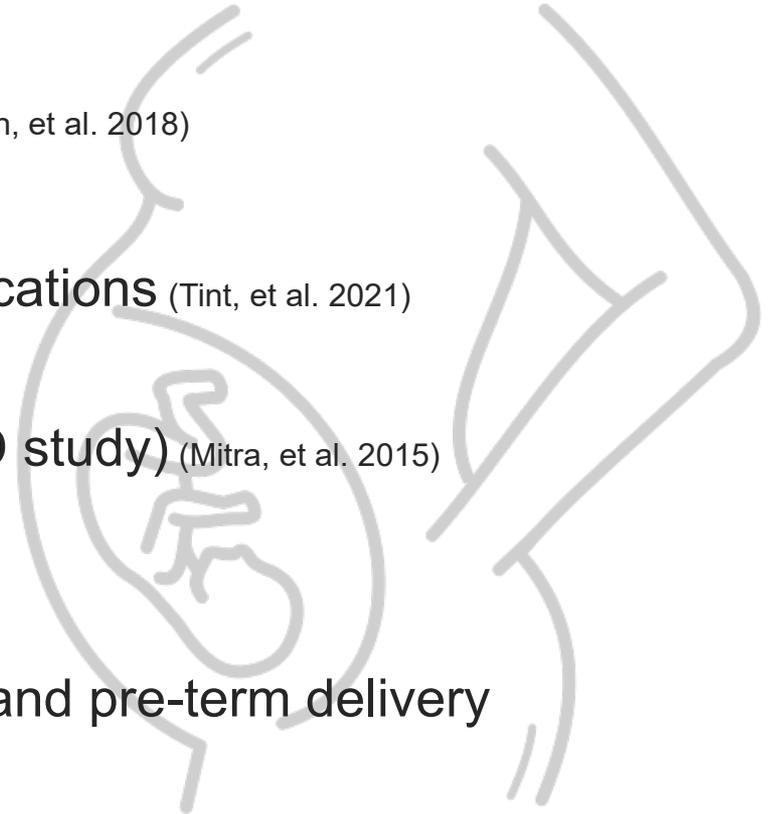
# Little research on pregnancy in autistic people, including obstetric risks and quality of prenatal care

## Health risk factors ~ obstetric complications:

- ↑ BMI (Sundelin, et al. 2018)
- ↑ Smoking during early pregnancy (Sundelin, et al. 2018)
- ↑ Anxiety and depression
  - ↑ use of potentially **teratogenic** medications (Tint, et al. 2021)
- ↓ Prenatal care in the first trimester (IDD study) (Mitra, et al. 2015)

## Pregnancy complications:

- ↑ Pre-eclampsia, gestational diabetes, and pre-term delivery (Sundelin, et al. 2018)

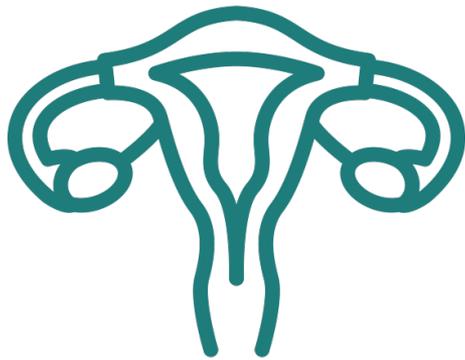


# Understanding barriers to reproductive health services may inform improvements to healthcare delivery

- Adult primary care + OB/GYN providers have little to no training in caring for autistic patients
- Assumptions about patient's sexual activity
- OB/GYN initiation may be delayed during the health care transition
- Hypersensitivity and aversion to touch and other sensory stimuli in OB/GYN visit
- People with gender dysphoria or gender-expansive identities may experience unique barriers in accessing care



# Study aims



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- What does the OB/GYN utilization of autistic people look like in a large US sample?
- What are the factors associated with utilization of OB/GYN care among autistic people compared with people with other developmental disabilities and people with neurotypical development?

# Study Methods

- Study setting: Kaiser Permanente Northern California (4.5 million members)
- Identified 3 groups of adults (aged 18+):
  - Autism (N=1438)
  - Other developmental disabilities (Cerebral palsy, intellectual disability) (N=3351)
  - Neurotypical development (N=5752)
- Neurotypical group matched 4:1 on age and membership length to autism group
- Members for at least 6 months of each year between 2017-2019



# Assessment of health and healthcare use

- Examined medical and psychiatric diagnoses, health care visits, prescriptions, and healthcare procedures during 2017-2019
  - This presentation is about:
    - visits to OB/GYN providers, excluding prenatal care
    - preventive care (e.g., cervical cancer screenings, mammograms)
    - hormonal contraception



# Takeaways

- In comparison with neurotypical people, autistic people have ↓ utilization of multiple types of reproductive health care including visits to the OB/GYN, routine screenings, and use of hormonal contraception.
  - Utilization generally similar between autistic people and people with other developmental disabilities.
- Many of these disparities emerge early in adulthood (i.e., transition period)
- Findings reflect care in an integrated healthcare system with strong outreach programs for preventive care.
  - Disparities likely larger in the broader US population.

# Ongoing analyses: Gynecology

- What are the shared and unique predictors of OB/GYN care in each of these groups?
- What does sexual and reproductive healthcare look like during the transition period (adolescence-early adulthood)?
- How did the COVID-19 pandemic influence use of OB/GYN care in 2020?

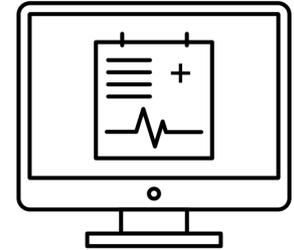


Image Stephanie King

# Ongoing analyses: Pregnancy and obstetric care

- **Objective:** To describe the epidemiology of pregnancy and prenatal care utilization
- **Study Design:** ~ 200 autistic people with pregnancy history, 340 pregnancies
  - Comparison to DD and neurotypical groups

Pregnancy complications and birth outcomes, e.g.,

- Pre-eclampsia
- Perinatal depression
- Preterm birth

Prenatal care and routine screening, e.g.,

- Ultrasound at 21 weeks
- Gestational diabetes
- Prenatal vaccinations



# Implications of this research for healthcare improvements

- Improving access to healthcare that is neurodivergent competent
- Educational resources to help people with intellectual and developmental disabilities manage reproductive health throughout lifespan
- Opportunities for patient and/or provider-facing tools for OB/GYN care

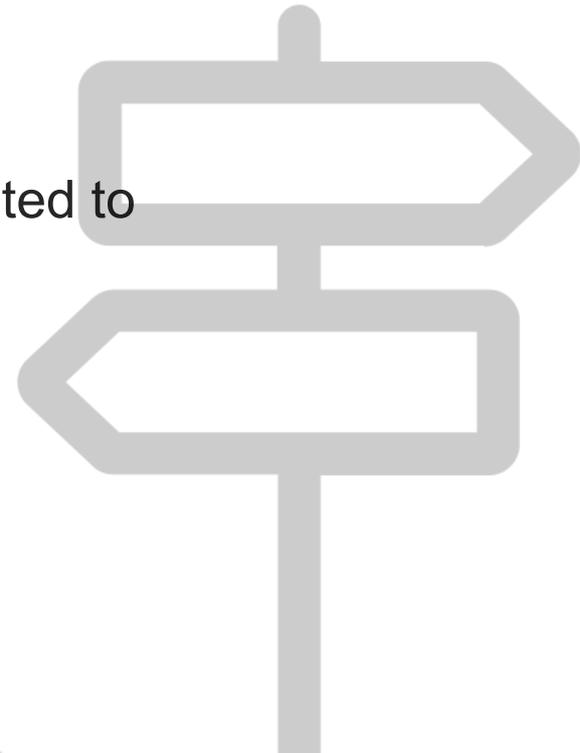


# Other notable gaps in reproductive health

- Need for qualitative research, for deeper understanding

- Health and healthcare experiences related to

- Puberty
- Menopause
- LGBTQIA+ health



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THANK YOU!

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**AIR-P Gender, Sexuality, and  
Reproductive Health Node**

GSR Advisory Committee

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- Please reach out if interested in learning more about the node's activities
- Eager to help develop, connect, and expand the network of researchers working to address these topics





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Thank you for attending!

A link to view the recording will be emailed to all registrants.

We hope to see you next month!

**Friday September 24, 2021**

**4:00 p.m. - 5:00 p.m. ET**

**AIR-P Genetics Research Node**

**By Dr. Julian Martinez, MD, PhD**

*Genetics AIR-P Research Node  
Leader*

[Register:](#)

