AIR-P Presents:

Addressing reproductive health and obstetrics/gynecology health care in autistic adults
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The data shown is 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

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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
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

Clinical implications

Data gaps and future directions
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)


- Few studies have focused specifically on reproductive healthcare of people with developmental disabilities such as autism

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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)
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

• 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?
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
References


Smeltzer SC. Preventive health screening for breast and cervical cancer and osteoporosis in women with physical disabilities. *Fam Community Health*. 2006;29(1 Suppl):35S-43S.


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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