

# Analyzing access to modern contraception among women with developmental disabilities in North Carolina: A mixed-methods study

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Big Data for Reproductive Health

## ABSTRACT

- Women with intellectual and developmental disabilities (IDD) have similar age-specific fertility rates<sup>1</sup> and are more likely to engage in unsafe sex.<sup>2</sup> However, significant barriers to accessing contraception exist, such as restricted decision-making power and discrimination in health care settings.<sup>3</sup>
- Comprehensive state-level data regarding contraceptive access in North Carolina is currently lacking, public surveys may exclude individuals who live in institutional settings or require communication assistance, and little is known about the landscape of reproductive health within residential facilities.
- This mixed-methods study aims to identify differences in contraceptive access among women of reproductive age with and without IDD by procedure type, contraceptive type, and facility type, as well as understand barriers to care provision.
- We will apply big data techniques to NC Medicaid claims data and conduct interviews with staff at residential facilities.
- Analysis will be conducted from February to July 2022, with the final goal of a manuscript to inform policy initiatives.

## MEDICAID DATA ACCESS

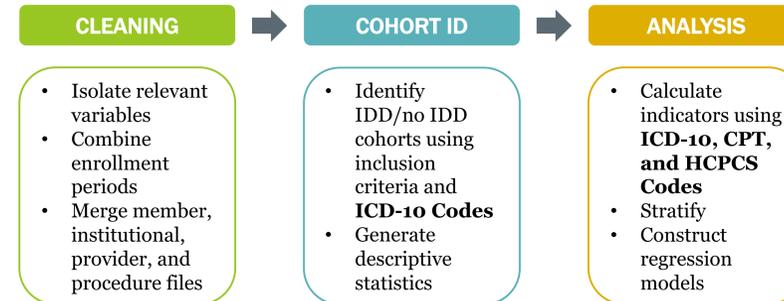
- 2/21** **DPHS PARTNERSHIP**
  - Establishment of working relationships with Duke Population Health Sciences DataShare staff
  - Orientation to access process and timeline
- 3/21 – 6/21** **RESEARCH & ANALYSIS PLAN**
  - Conduct background research
  - Collaborate to identify analysis approach
  - Integrate multisource expert feedback
  - Draft statistical analysis plan and tables
- 7/21 – 9/21** **DUKE APPROVALS**
  - Receive DPHS NC Medicaid Review Committee approval of request forms
  - Complete required trainings and receive Duke Health IRB exempt study approval
- 10/21** **NC DHHS APPROVAL**
  - Send finalized submission packet to DPHS for preliminary review
  - Receive NC DHHS HIPAA Compliance and Medicaid Review Committee approval
- 11/21 – 1/22** **TRAINING & CONFIGURATION**
  - Complete CITI and Learning Management System trainings
  - Submit PACE-FISMA requests
  - Configure workspaces and project folder
  - Orient to Oracle, SAS, and data structure

## QUANTITATIVE METHODS

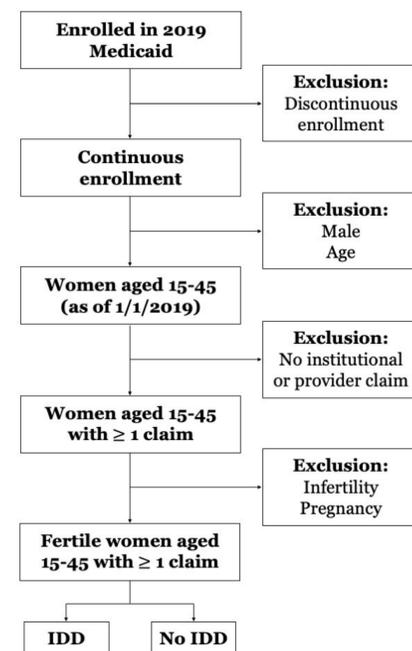
### PRIMARY AIMS

1. Characterize contraceptive health care utilization by procedure type, contraceptive type, facility type, and sociodemographic characteristics
2. Identify associations between IDD and contraceptive health care utilization through regression analysis

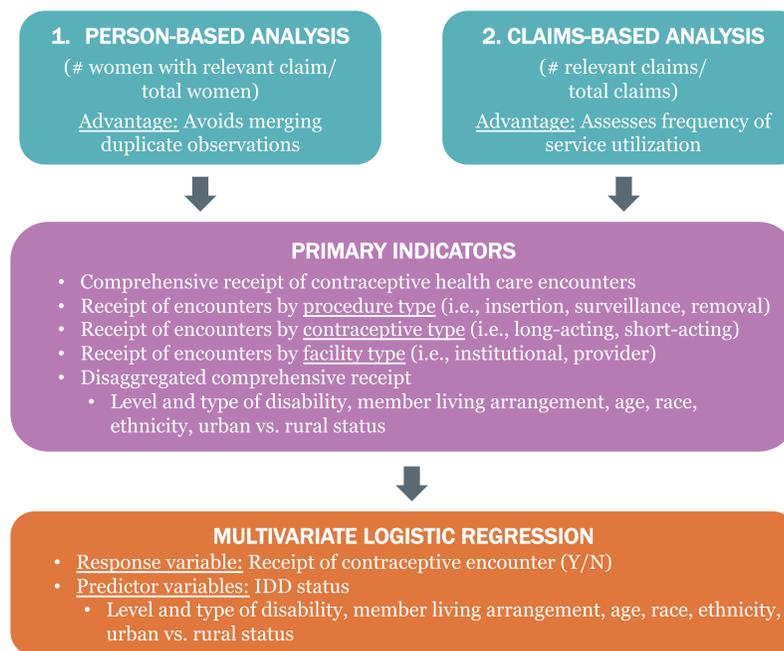
### PROCESS OVERVIEW



### COHORT IDENTIFICATION



### ANALYSIS APPROACH



## QUALITATIVE METHODS

### PRIMARY AIMS

1. Explore sexual and reproductive health care offerings at both public and private IDD residential facilities in North Carolina
2. Compare perspectives of administrators, clinicians, and social workers surrounding contraceptive provision and utilization

### PROCESS



### INTERVIEW THEMES

- 1 General practices and resident care
- 2 Provision of reproductive health care
- 3 Contraceptive offerings and utilization
- 4 Perceptions of patterns and needs

## LESSONS LEARNED

### SIGNIFICANCE OF INTERDISCIPLINARY PARTNERSHIP

Throughout project development, we gathered insight from an interdisciplinary team of experts (e.g., biostatisticians, IDD experts, OB-GYNs, etc.), which led to continual refinement our analysis plan and interview guide.

### VALUE OF DETAIL-ORIENTED MANAGEMENT AND COMMUNICATION

Accessing Medicaid data, navigating analysis, and overseeing multiple project streams are complex processes that benefit from precise planning, active teamwork, and frequent reporting across all project partners.

### RESEARCH REQUIRES TIME, PATIENCE, AND PERSISTENCE

Frequent and inevitable logistical barriers encountered throughout the course of the project have required flexibility and resilience. While anticipated timelines may extend, thorough consideration of challenges results in higher quality research.

## NEXT STEPS

- 4/22 – 5/22** **COMPLETE ANALYSES**
  - Finalize person-based analysis
  - Merge duplicate observations and execute claims-based analysis
- 6/22** **CONDUCT INTERVIEWS**
  - Recruit administrators, clinicians, and social workers from residential facilities
  - Conduct interviews via Zoom
- 7/22 – 8/22** **INTERPRET FINDINGS**
  - Compare claims-based vs. person-based results
  - Analyze qualitative interview data
- 9/22 – 11/22** **PREPARE MANUSCRIPT**
  - Produce mixed-methods publication for journal submission
  - Disseminate findings to key stakeholders

1. Brown, H. K., Lunsby, Y., Wilton, A. S., Cobigo, V., & Vigod, S. N. (2016). Pregnancy in Women With Intellectual and Developmental Disabilities. *Journal of Obstetrics and Gynaecology Canada*, 38(1), 9–16.  
2. Baines, S., Emerson, E., Robertson, J., & Hatton, C. (2018). Sexual activity and sexual health among young adults with and without mild/moderate intellectual disability. *BMC Public Health*, 18(1), 667.  
3. National Partnership for Women & Families & Autistic Self Advocacy Network (2021). *Access, Autonomy, and Dignity: Contraception for People with Disabilities*.

\*Project data made available through partnership between Duke Population Health Sciences and the North Carolina Department of Health and Human Services