

# Gynecological Needs for People with Intellectual and Neurodevelopmental Disabilities: A Survey of START-enrolled Women

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## Abstract

In 2023, NIH finally recognized people with disabilities as having healthcare disparities (.S. Department of Health and Human Services 2023). People with autism are more likely to access emergency medical services than the general population for both psychiatric and non-psychiatric emergencies (Vohra et al. 2016). Individuals with Intellectual Disabilities are more likely to have a long list of medical comorbidities, including Type II Diabetes, Epileptic and non-Epileptic seizures, chronic constipation, acid reflux, allergies and sleep disorders.

More specifically, women with intellectual/developmental disabilities have greater disparities compared with women without disabilities (Tarasoff et al. 2020). One area that is under-explored is gynecological care for women with ASD and IDD. Gynecology visits are less common among autistic women than the general population (Tint et al. 2023) and women with intellectual disability are at greatest risk of experiencing barriers to gynecological care (Agaronnik 2020). Antenatal care is not adapted for patient education of pregnant people with Intellectual Disabilities, much of which is text-based (Homeyard and Patelarou, 2018). There are few known sites with gynecological services designated for persons with Intellectual Disabilities in the Triborough region, so it is likely that there is no gynecological patient education adapted for people with ID/D, either.

Agaronnik, N., Pardo, E., Laga, T., DeLong, C., Perez-Caraballo, A., & Iezzoni, I. I. (2020). Ensuring the Reproductive Rights of Women with Intellectual Disability. *Journal of Intellectual & Developmental Disability*, 45(4), 305-316. <https://doi.org/10.1080/13687875.2020.1823289>

Greenwood, M. W., & Wilkinson, J. (2013). Sexual and reproductive health care for women with intellectual disabilities: a primary care perspective. *International journal of family medicine*, 20(1), 64-67. <https://doi.org/10.1155/2013/646472>

Tarasoff, L. A., Varney, S., Chen, S., Guterman, A., Haverkamp, S. M., Parish, S. L., Migid, S. N., Carls, A., & Brown, H. K. (2020). Preconception Health Characteristics of Women with Disabilities in Ontario: A Population-Based, Cross-Sectional Study. *Journal of women's health* (2020), 29(12), 1694-1697. <https://doi.org/10.1089/jwh.2019.0273>

Tint, A., Chung, H., Liu, M. C., Shagle, R., Lin, E., Garcia, A., & Lundy, V. (2023). Health conditions and service use of autistic women and men: A retrospective population-based case-control study. *Autism: the international journal of research and practice*, 27(6), 1645-1657. <https://doi.org/10.1177/13646332231164444>

U.S. Department of Health and Human Services. (2023, September 26). *Emergency Department Use Among Adults with Autism Spectrum Health Disparities*. National Institutes of Health. <https://www.nih.gov/news-events/news-releases/nih-disparities-people-disability-population-health-disparities>

Vohra, S., Haddaway, S., & Sandhammar, U. (2016). Emergency Department Use Among Adults with Autism Spectrum Disorders (ASD). *Journal of autism and developmental disorders*, 46(4), 1441-1454. <https://doi.org/10.1007/s10803-015-2692-2>

## Objectivity and Aims

In some states across the nation, women's access to healthcare is being restricted. However, many of the women supported by START struggle to access women's health as it is. We wanted to get quantitative data exploring how many START-enrolled women are accessing gynecological services, and for those who are not, what are the barriers.

## Methodology

Assigned Coordinators completed a survey of START-Enrolled women where we asked them

1. Do they go to the OBGYN
2. If so, where ?
3. If not, why not? (left open-ended)

We then looked at their social history to assess for additional patterns

1. History of sexual abuse
2. History of ACS involvement or foster care

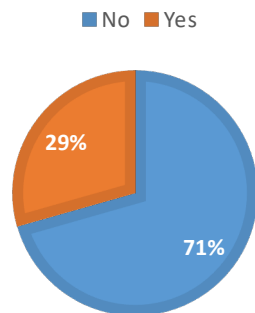
## Case Study

- Mindy\* is a 42-year-old African American woman living in a group home.
- Almost daily, Mindy reports to her staff that **her stomach is hurting** and asks that they call 911. This culminates in an emergency room visit 30% of the time.
- **Her Life Plan states "My health is stable."** It notes that in the past year, she has been to the hospital several times for "ongoing medical issues and behavior issues" (none specified).
- Health needs are noted to be sleep apnea, asthma and the need of oxygen tank. It is noted in her Life Plan that she receives gyn services at the NY Presbyterian Center for Developmental Delays in Queens.
- Mindy spent 2 months at King's County Hospital's IDD/Behavioral Health unit for psychiatric stabilization.
- Medical conditions listed in the dc summary include sleep apnea, asthma, history of seizures, kidney disease, and hypertension. Hospitalization did not decrease Mindy's complaints of stomach pain.
- **Mindy has fibroids. She is not going to the OBGYN.** Staff reports that she declines her appointments. This challenges is not documented.

\*name has been changed

## Analysis

### RESPONDENTS WHO GO TO THE GYN



### 70% do not go to the OBGYN

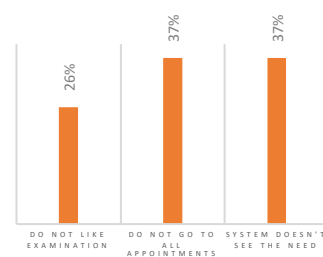
#### For those who go:

- 75% go to hospital-based Women's Clinic
- 25% go to IDD-Specialized clinic

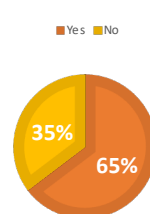
#### For those who do not:

- 75% have been in foster care (vs 65%)
- No significant differences in sexual assault history between those who do and do not go to the GYN

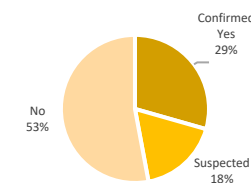
### REASONS FOR NOT GOING



### HISTORY OF FOSTER CARE



### History of Sexual Abuse



"Women's rights are human rights"  
- Hillary Rodham Clinton

## Implications & Limitations

- The majority of START-supported women do not go to the OBGYN
- Many women can't access IDD-specific gynecologists
  - Many IDD-Health clinics lack gynecological services
- Visit length (determined by insurance) may create a barrier:
  - Does not accommodate women who need special accommodations (social stories, emotional support)
  - Does not accommodate women who have been sexually abused
- Gyn issues are likely missed in women who routinely miss doctors appointments
- Our survey relied on staff-reporting, who missed diagnosed gynecological issues in some women