Comparison of Healthcare Utilization Among Patients with Down Syndrome in Specialty Care vs Non-Specialty Care

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BACKGROUND

- Down syndrome (DS) is the most common chromosomal abnormality in the US. Due to medical advancements, the average lifespan for individuals with DS (IWDS) has doubled to approximately 60 years over the past 40 years
- Only 5% of adolescents and adults with DS receive care from DS specialist providers
- The Adult Down Syndrome Center (ADSC) is the largest dedicated adult DS clinic in the US, with 7 specialized DS providers treating approximately 1,800 unique patients annually
- Specialized clinics provided tailored clinical guidance, however data on healthcare utilization of specialized vs. non-specialized DS primary care is limited

STUDY OBJECTIVE

Evaluate the impact of exclusive DS-specialized primary care on healthcare utilization compared to exclusive standard primary care, as a foundation on further research on specialty care for IWDS

METHODS/ANALYSES

- **Study design**: Retrospective cohort study to compare healthcare utilization among IWDS ages 12+ years who engaged with a primary health provider at Advocate Health healthcare system (AH) between 01/01/2018 to 5/31/2025
- **Index date**: First encounter with a primary care provider within study timeframe

Comparison Groups (Mutually Exclusive)

- **ADSC cohort:** IWDS who exclusively had encounters with a DS-specialized primary care provider at ADSC (n = 799)
- **Non-ADSC cohort**: IWDS who exclusively had encounters with a non-DS specialized primary care provider at another clinic within AH (n = 704)
- Average follow up in months was 39.9 and 37.3 for ADSC and Non-ADSC cohorts respectively

Statistical Analyses

- Baseline characteristics were balanced using inverse probability treatment weighting (IPTW)
- Covariates included in the propensity score used to generate IPT weights were age at index (continuous [cont.]), sex (categorical [cat.]), race/ethnicity (cat.), insurance type (cat.), pre-Index AH encounter (cat.), total number of pre-index encounters (cont.), pre-Index inpatient encounters (cont.), pre-Index emergency department (ED) encounters (cont.)
- Weighted negative binomial model to estimate the risk of healthcare utilization for ADSC cohort vs. Non-ADSC cohort
- Models were adjusted for age at index, sex, insurance type, race/ethnicity, prior AH encounter, and follow up months
- All analyses were done using R v4.5.1

STUDY POPULATION

Table 1. Baseline Demographic & Healthcare Utilization Characteristics Prior to Index Date

Characteristic	ADSC cohort (n = 799)	Non-ADSC cohort (n = 704)	SMD
Age at index date mean (SD), years	35.0 (13.4)	31.4 (14.3)	0.3
12-17 years, n (%)	35 (4.4)	118 (16.76)	
18-35 years, n (%)	210 (26.3)	185 (26.28)	
≥ 35 years, n (%)	223 (27.9)	155 (22.0)	
Female, n (%)	360 (45.1)	394 (56.0)	0.2
Race/ethnicity, n (%)			0.4
NH White	591 (74.0)	403 (57.2)	
Hispanic	77 (9.6)	114 (16.2)	
NH Black	54 (6.8)	117 (16.6)	
NH Other RE	28 (3.5)	30 (4.2)	
Unknown	49 (6.1)	40 (5.7)	
Insurance type, n (%)			0.5
Commercial/Other	267 (33.4)	291 (41.3)	
Medicaid	138 (17.3)	211 (30.0)	
Medicare	394 (49.3)	202 (28.7)	
Any pre-index date AH encounter (y/n)	355 (44.4)	444 (63.1)	0.4
Total encounter, mean (SD)*	3.7 (7.7)	6.7 (12.8)	0.3
Inpatient visit, n/N (%) *	22/355 (6.2)	87/444 (19.6)	0.4
ED visit, n/N (%)*	37/355 (10.4)	106/388 (23.9)	0.4

SMD, Standardized mean difference; SD, Standard deviation

*Among those with ≥ 1 AH encounter prior to index date

RESULTS

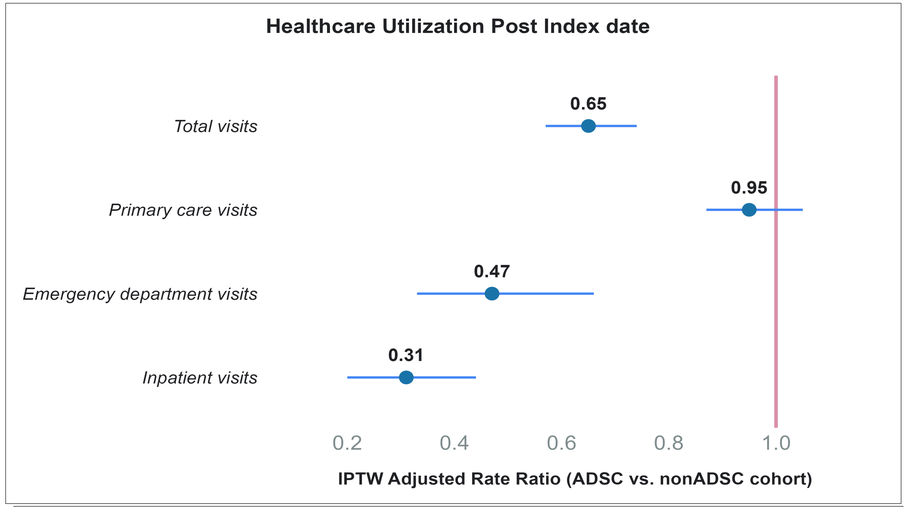

Figure 1. Association between specialty care and healthcare utilization. Values to the left of the solid pink line indicate a lower rate among the ADSC cohort and those to right indicate a higher rate among the ADSC cohort
All p values < 0.05 except primary care visits
IPTW, Inverse probability treatment weighted

CONCLUSIONS/FUTURE WORK

- The ADSC cohort had similar amounts of primary care visits but 53% fewer emergency department & 69% fewer inpatient stays
- **Next steps**: Evaluate adherence to medication therapies and All-Cause readmission patterns between groups

REFERENCES

Please contact study team for list of references

Advocate Medical Group®
Adult Down Syndrome Center

Scan here to learn more about the ADSC!

Contact Dr. Brian Chicoine with any additional questions:
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