

The Colorado Autistic Perinatal Experience

A Claims-Based Study of Pregnancy and Delivery

DARCY HOLLADAY FORD, KIMI LANDRY, MEGHA JHA, RACHEL JARDIM

Research Objective

To describe pregnancies and deliveries among autistic individuals in Colorado using the Colorado All Payer Claims Database (CO APCD), and to inform future interventions aimed at improving perinatal outcomes and reducing complications.

Background

- Maternal mortality and morbidity are significant concerns across the US (Gunja et al., 2024; Hoyert, 2023).
- The autistic adult experience is rarely studied, especially during the perinatal period (Fujiwara et al., 2014; McDonnell et al., 2021).
- Small observational studies indicate autistic individuals experience lower provider satisfaction due to communication mismatches, and increased pregnancy-related anxiety, depression, stigma, comorbidities, and postpartum complications (Hampton et al., 2024; McDonnell et al., 2021; Thom-Jones et al., 2024).

Study Design

Retrospective cohort analysis of CO APCD claims (2012-2023), allowing for an extensive population analysis using the:

- Identified Pregnancy and Delivery: Validated Johns Hopkins ACG Adjusted Clinical Groups System
- Stratified the population by:
 - Age group
 - Insurance type (Medicaid, Commercial, Medicare)

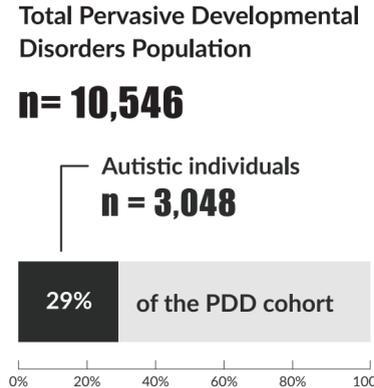
Cohort

Included

- Individuals with PDD identified via ICD 10 (F80-89), ICD-9 (315 & 299)
- Autistic Individuals (ICD 10 (F84), ICD 9 (299))
- Pregnancies and deliveries regardless of outcome

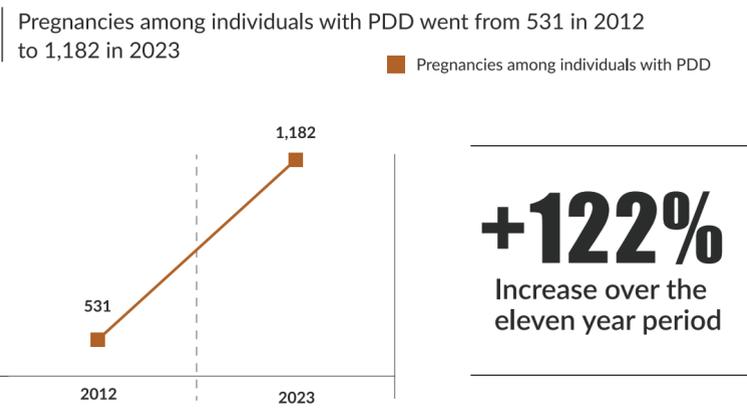
Excluded

- Dual-eligible Medicare/Medicaid individuals
- Individuals without an ACG-identified pregnancy or deliveries

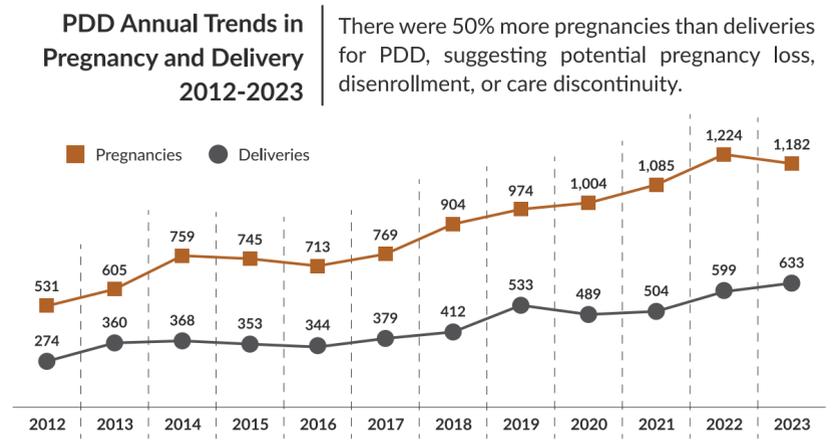


Principle Findings

Increasing PDD Pregnancies

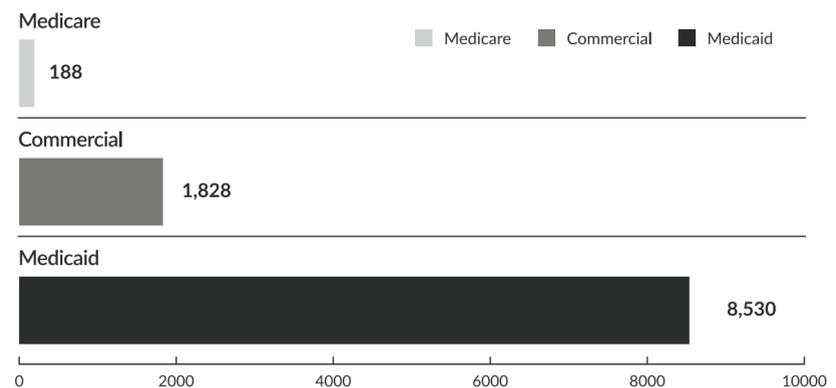


Pregnancy vs. Delivery Gap



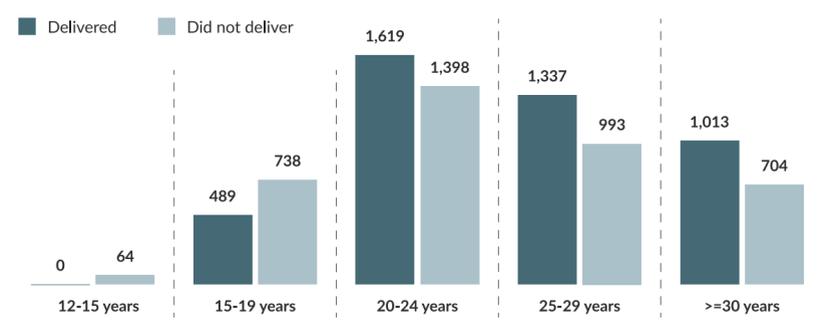
Insurance Coverage

PDD Insurance Coverage Among Pregnant and Delivered | 2012-2023

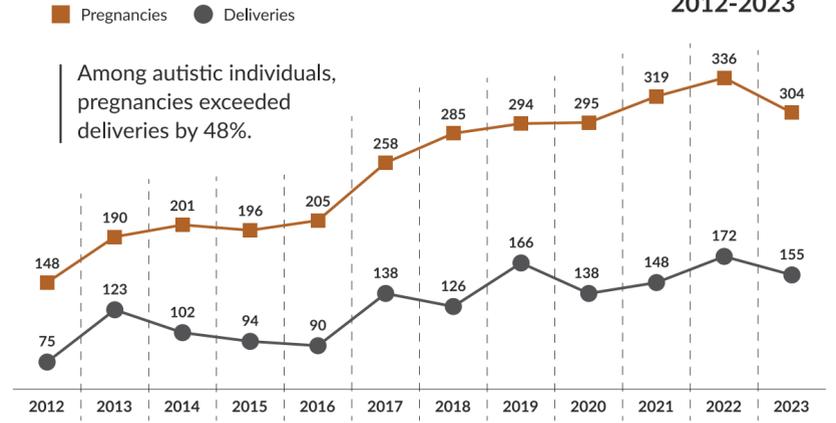


Age Distribution

PDD Delivery Outcomes by Age Group | 2012-2023



Annual Trends in Pregnancy and Delivery Among Autistic Individuals 2012-2023



81%

Most pregnant individuals with PDD relied on Medicaid (81%), highlighting high social and economic vulnerability in this population.

Implications for Policy or Practice

- Autistic and PDD-identified individuals face a significant gap between pregnancy and delivery points, which points to missed care, loss, or system breakdowns, yet remain largely invisible in perinatal care efforts.
- This work echoes prior research showing higher disease burden and earlier mortality among autistic individuals (Shaw et al., 2023).

Conclusions

- Autistic individuals represent a high-medical need and social vulnerability population, with over 80% covered by Medicaid or Medicare.
- Findings reinforce the urgent need for tailored perinatal interventions to improve outcomes and promote maternal health equity.
- This study demonstrates the power of claims data to identify inequities and inform targeted, data-driven maternal health strategies.

References

Cadden, R., & Charnock, D. (2025). An extended literature review into the perinatal experiences of autistic women. *MIDIRS Midwifery Digest*, 35(1). Retrieved from <https://www.researchgate.net/publication/390023743>

Hampton, S., Allison, C., Baron-Cohen, S., et al. (2024). Autistic people's perinatal experiences I: A survey of pregnancy experiences. *Journal of Autism and Developmental Disorders*, 54, 211-223. <https://doi.org/10.1007/s10803-022-05754-1>

Hoyert, D. L. (2023). Maternal mortality rates in the United States, 2021. *NCHS Health E-Stats*. National Center for Health Statistics. <https://doi.org/10.15620/cdc:124678>

Fujiwara, T., Kasahara, M., Tsujii, H., & Okuyama, M. (2014). Association of maternal developmental disorder traits with child mistreatment: A prospective study in Japan. *Child Abuse & Neglect*, 38(8), 1283-1289. <https://doi.org/10.1016/j.chiabu.2014.04.007>

Gunja, M. Z., Gumas, E. D., Masitha, R., & Zephyrin, L. C. (2024). Insights into the U.S. Maternal Mortality Crisis: An International Comparison. *The Commonwealth Fund*. <https://doi.org/10.26099/cthn-st75>

McDonnell, C. G., & DeLucia, E. A. (2021). Pregnancy and parenthood among autistic adults: Implications for advancing maternal health and parental well-being. *Autism in Adulthood*, 3(1), 100-115

Shaw, S. C., Carravallah, L., Johnson, M., Chown, N., Neilson, S., & Doherty, M. (2023). Barriers to healthcare and a 'triple empathy problem' may lead to adverse outcomes for autistic adults: A qualitative study. *Autism*. <https://doi.org/10.1177/13623613231205629>

Suzumura, S. (2015). Quality of life in mothers of preschoolers with high-functioning pervasive developmental disorders. *Pediatrics International*, 57(1), 149-154. <https://doi.org/10.1111/ped.12560>

Tanguay, P. E. (2000). Pervasive developmental disorders: A 10-year review. *Journal of the American Academy of Child & Adolescent Psychiatry*, 39(9), 1079-1095. <https://doi.org/10.1097/00004583-200009000-00007>

Thom-Jones, S., Melgaard, I., & Gordon, C. S. (2024). Autistic women's experience of motherhood: A qualitative analysis of Reddit. *Journal of Autism and Developmental Disorders*. Advance online publication. <https://doi.org/10.1007/s10803-024-06312-7>



Scan the QR code to view the full Colorado Autistic Perinatal Experience abstract

To access the full Colorado Autistic Perinatal Experience abstract and to learn more about public and non-public CO APCD data, visit civhc.org

