



Improving Inclusivity in Patient Experience Data

Nicole Leonick, BS¹, Mary J. Monari-Sparks, MD², Franziska F. Jovin, MD, MMM², Pashchima Kamal, MS²

¹Cooper Medical School of Rowan University, Camden, NJ 08103

²Cooper University Hospital, Camden, NJ 08103



Introduction

- The U.S. Health and Human Services highlights a critical lack of data on the health and well-being of individuals with IDD largely due to their exclusion from research.
- Restricting IDD involvement in initiatives intended to drive change limits understanding of their needs and insight into issues that disproportionately affect them.
- This project reviews IDD patient survey response rates at our institution to address the underrepresentation of the IDD community in healthcare and highlight the need for better engagement methods.



In the U.S., approximately 1 in 6 children aged 3 through 17 have a developmental disability, and globally, about 1 in 6 people experience significant disability.

Methods

- A retrospective review of 1,207 patients from our IDD Epic registry assessed medical practice survey return rates from January 2019 to October 2024.
- Included patients meet the American Association on Intellectual and Developmental Disabilities and DSM-5 criteria for IDD.
- Standardized surveys covered domains such as access, efficiency, interpersonal quality, privacy and safety, personalization, and compassion.
- Surveys were completed by patients or their caregivers and returned via mail or online submission.
- The analysis focused on ambulatory settings, where IDD patients receive consistent care, and where future targeted survey efforts can be most effectively implemented.



89.9%

In published child development research, 89.9% of studies excluded children with disabilities, even though reasonable accommodations could have allowed their inclusion in approximately 70% of them.



74.6%

An analysis of 263 NIH-funded trials from 2018 to 2021 found that 74.6% of studies excluded adults with IDD, and 33% had exclusion criteria for cognitive impairment or intellectual disability.



107.62 million people

In 2019, an estimated 107.62 million individuals with intellectual disabilities comprised the global population.



7.39 million people

In 2019, of the 7.39 million people in the U.S. with intellectual disabilities, only 22% were known to state agencies, and just 19% received long-term services beyond case management.



2x risk

According to the WHO, individuals with disabilities face double the risk of developing conditions like depression, asthma, diabetes, stroke, obesity, and poor oral health due to systemic health inequities.



20 years lost

The WHO also states that people with disabilities may die up to 20 years earlier than those without disabilities, largely due to widespread barriers to healthcare.



Intellectual Developmental Disabilities (IDD) Patient Experience Survey

Your Opinion Matters!

We'd love to hear from you. Please take a moment to share your thoughts on how we are doing as a team and as an organization. Your feedback is invaluable and helps us grow.



We welcome your suggestions and ideas!

Cooper
University Health Care



Please scan the QR code to take a brief survey.

Conclusion

- Using patient-reported experiences in decision-making improves outcomes and fosters a more inclusive, responsive care environment—especially for underserved groups like those with IDD.
- Survey data reflecting IDD patient narratives makes up less than 1% of outpatient clinic feedback, revealing a crucial gap in data used to inform care decisions.
- While the reasons for low response rates are still being explored, IDD patients and their caregivers urgently need more accessible platforms to share their experiences.
- A targeted, IDD-focused survey would improve outreach, capture more representative feedback, and help ensure that healthcare decisions and clinical care better align with their needs.

Acknowledgements

Thank you, Dr. Monari-Sparks, Dr. Jovin, Ms. Kamal, Cooper Medical School of Rowan University, and Cooper University Hospital, for your support and insight throughout this project.

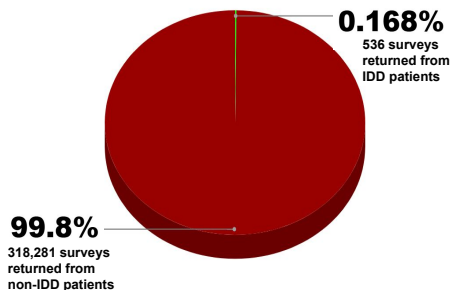
Further, thank you to the American Academy of Developmental Medicine & Dentistry for accepting our abstract and providing a platform to share our work.

References



Results

Cooper Survey Responses: IDD vs. Non-IDD Patients



1,207 patients

There were 1,207 total patients on Cooper's Epic IDD registry at the time of analysis.

230 patients

Only 230 patients submitted surveys

Just 19.1% of Cooper's IDD population is represented in feedback-driven decisions.

7 patients

118 of the IDD surveys came from just seven MRNs, indicating that 22% of the data reflects responses from only seven patients.

0 patients

Shared addresses and emails prevented survey access for group home residents, resulting in 0 responses from that population.