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Abstract Title

ADORE: Understanding the Presentation and Service Needs of Manitoba Children with Autism and Building a Longitudinal Epidemiological Dataset

Authors

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Will they participate in the poster presentation at CHRD?

No

Background

Although Canada has established longitudinal autism research cohorts, there remains a gap in prospective, province-wide clinical data capturing young children diagnosed with autism within a publicly funded health-care system.

Objective

Building on Manitoba's centralized autism diagnostic pathway for children 6 years and younger, the Autism Diagnostic Outcomes Registry (ADORE) was established to prospectively characterize the referral and diagnostic pathway, clinical presentation, and service needs of this population. We present the first analysis of the ADORE cohort.

Methods

ADORE was initiated as a 3-year project, with prospective data collection beginning November 1, 2023. A

standardized data collection form and detailed data dictionary were developed, and data were collected at the time of diagnosis by two trained allied health professionals. On June 1, 2026, provincial policy changes allowed community pediatricians to diagnose autism, altering the centralized referral pathway. Therefore, this first analysis includes diagnosed through the Rehabilitation Centre for Children (RCC) between November 1, 2023, and June 1, 2026. All analyses were conducted using completely anonymized, aggregate data.

Results

A total of 1,770 children were diagnosed with autism during the study period. Most were male (72.2%), and 65% resided in Winnipeg. Autism severity was Level I in 12.3%, Level II in 49.5%, and Level III in 38.2%. Twenty-five percent lived in single-parent households, and 35.3% had a confirmed immigrant background, with an additional 7.7% with highly suspected immigration (43%). Indigenous identity was reported in 22.3% of cases. A first-degree family history of autism was reported in 15.4%, and 18% of parents reported a mental health condition. Among children from families with Indigenous identity, autism severity was Level I in 3.8%, Level II in 40.5%, and Level III in 55.7%. Most children were born at term, 0.8% born at <29 weeks (12.1%) at 29–32 weeks. Common co-occurring conditions included allergy (10%), sleep difficulties (9%), and dermatological conditions (6.7%).

Conclusion

ADORE provides a unique province-wide epidemiological registry of young children diagnosed with autism through Manitoba's centralized diagnostic system. This first analysis demonstrates the breadth of clinical and sociodemographic information captured. Continued follow-up and linkage with population-level administrative health and social data have the potential to transform ADORE into a longitudinal epidemiological dataset examining developmental trajectories, service utilization, and outcomes among children with autism in Manitoba.