

Support NH HB 1316

Talking Points

Restricting the collection and disclosure of autism-related data by state agencies

HB 1316 protects civil rights, privacy, and bodily autonomy.

- HB 1316 ensures that autism-related data is collected only when absolutely necessary and only in compliance with federal privacy law, including HIPAA. Autism status is protected health information, and improper data collection creates serious risks of discrimination, profiling, and harm.
- Federal law requires health data to be minimally collected, purpose-limited, and strictly safeguarded. This bill ensures New Hampshire aligns fully with those protections.

Source: U.S. Department of Health & Human Services, HIPAA Privacy Rule, 45 CFR §164.502

Data misuse puts people with disabilities at real risk of discrimination.

- Research consistently shows that disclosure of disability status, particularly autism, can lead to employment discrimination, educational exclusion, housing bias, insurance barriers, and social stigmatization.
- A 2023 National Academies of Sciences report found that medical data misuse significantly increases discrimination risk, especially for people with developmental disabilities.

Source: National Academies of Sciences, Health Data Privacy & Equity, 2023

Autism registries and tracking systems have historically caused harm.

- Studies show that autism registries, when misused, lead to increased stigma, surveillance, and mistrust, particularly among marginalized communities.
- The American Academy of Pediatrics cautions that large-scale tracking systems discourage families from seeking diagnosis and treatment, leading to worse health and educational outcomes.

Source: American Academy of Pediatrics, Ethical Issues in Autism Data Collection, 2021

Important Bill Information

Public Hearing: 02/04/2026
02:00 PM, Granite Place 158

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Surveillance and data scraping create profound civil liberties concerns.

- HB 1316 prohibits data scraping and unauthorized data aggregation, practices the Federal Trade Commission has repeatedly warned can violate civil rights, consumer protection laws, and medical privacy standards.
- In 2022, the FTC warned that data brokers and scraping technologies can expose sensitive disability-related data without consent, creating serious risks of exploitation, surveillance, and discrimination.

Source: Federal Trade Commission, Protecting Consumer Privacy in the Era of Big Data, 2022

Fear of surveillance reduces access to care.

- Multiple studies demonstrate that fear of data misuse discourages families from pursuing early diagnosis, interventions, and services, particularly among immigrant families, families of color, and families with low income.
- This means children lose critical early supports, resulting in poorer long-term outcomes and higher public costs.

Source: Journal of Autism and Developmental Disorders, 2022

Limiting unnecessary data collection strengthens public trust.

- Public trust is essential for effective healthcare, education, and social service systems. When families fear surveillance, they disengage.
- A 2023 Pew Research study found that 72 percent of Americans worry about how government agencies use sensitive health data, with disability-related data among the top concerns.

Source: Pew Research Center, Public Trust and Health Data Privacy, 2023

Strong privacy protections improve outcomes and reduce long-term public spending.

- When families trust service systems, they access care earlier, reducing reliance on emergency services, crisis interventions, and institutional placements.
- The CDC estimates that early autism interventions can reduce lifetime public costs by \$1 to \$2 million per individual through improved independence and employment outcomes.

Source: Centers for Disease Control and Prevention, Autism Economic Impact Analysis, 2023