



ANGELO SANTABARBARA, PE
Assemblyman 111th District

THE ASSEMBLY
STATE OF NEW YORK
ALBANY

CHAIR
Committee on
People with Disabilities
COMMITTEES
Energy
Governmental Employees
Mental Health
Racing and Wagering

May 15th, 2025

The Honorable Kathy Hochul
Governor of the State of New York
NYS State Capitol Building
Albany, NY 12224

Subject: Request for Executive Action Supporting Autism Data Privacy Legislation

Dear Governor Hochul,

As Chair of the Assembly Committee on People with Disabilities, I have introduced legislation to safeguard the privacy of New Yorkers with autism by limiting the unauthorized collection and disclosure of their identifiable health information. I respectfully request your support—and urge you to issue an executive order reflecting the principles outlined in this bill.

The Autism Data Privacy Protection Act draws on recent action taken in Illinois, where Governor J.B. Pritzker signed Executive Order 2025-02, making Illinois the first state to bar the release of autism-related health data to federal agencies or outside entities without informed, written consent.

That order received strong backing from:

- Autism advocacy organizations, including Autism Speaks;
- Disability rights groups concerned about surveillance and misuse;
- Civil liberties advocates, calling for stronger consent protections; and
- Privacy experts, who praised its focus on anonymization and data minimization.

In New York, my legislation would ensure:

- Personally identifiable autism-related health data may not be collected or disclosed by any state agency, contractor, or grantee without informed, written consent—unless otherwise required by law or court order;
- Any disclosure is limited to the minimum necessary and anonymized when feasible;
- Exceptions are permitted only for delivering essential services such as education, health care, employment, or housing.

While I will continue working to move this bill forward through the legislative process, executive action is needed now to establish immediate protections. Taking this step would not only reinforce the goals of my legislation—it would position New York as a national leader in defending disability rights and health data privacy amid increasing federal collection efforts.

This is a pivotal opportunity to take meaningful action on behalf of individuals with autism. I urge you to act swiftly and issue an executive order grounded in the framework of this legislation.

Sincerely,

A handwritten signature in black ink, appearing to read "Angelo Santabarbara". The signature is fluid and cursive, with the first name "Angelo" written in a larger, more prominent script than the last name "Santabarbara".

Angelo Santabarbara, PE

Member of the New York State Assembly

Chair, Committee on People with Disabilities

111th District | Representing areas of Montgomery & Schenectady Counties