

**Joint Statement on the Proposed Autism Registry by HHS Secretary Robert R. Kennedy Jr.
April 23, 2025**

From The Arc of Colorado, the Autism Society of Colorado, Colorado Cross Disability Coalition, Colorado Developmental Disabilities Council, Disability Law Colorado, Family Voices Colorado, PEAK Parent Center and Show & Tell.

As leaders of Colorado statewide disability organizations, we stand in support of Autistic individuals and their families. We are deeply concerned by growing [rhetoric](#) and policy decisions based on misinformation that perpetuate stigma. We call upon our public leaders, institutions and media to uphold evidence-based scientific integrity in public dialogue and policy decisions that reflect the inherent value, rights and diverse needs of the Autistic community.

On April 22, 2025, Health and Human Services Secretary Robert F. Kennedy Jr. [released plans](#) to collect data, including private medical records, from a number of federal and commercial databases. Those sources include medication records from pharmacy chains, lab testing and genomics data from patients treated by the Department of Veterans Affairs and Indian Health Service, claims from private insurers and data from smartwatches and fitness trackers. The plan also seeks to establish a disease registry to track Autistic Americans.

Data collection, analysis and interpretation are research tools used in clinical settings to understand and develop treatment and support services for people with an identified health need. Community leaders, trusted clinicians and Autistic people and their families are deeply concerned that proposed data collection efforts will move forward without adequate transparency, accountability or protection for Autistic individuals, based solely on their diagnosis. Many community members are unwilling to disclose their diagnosis to government entities due to fears of data misuse, discrimination or surveillance. Moreover, many Autistic people do not see autism as something to be fixed or studied. Disability is a normal part of the human experience.

We call upon our congressional leaders to ensure that any research approach includes clear ethical standards and disclosures. Individuals who choose to participate in research must also have the choice to opt in or out of data collection and must clearly understand what data is being collected, how it will be used and who will have access to it. We further declare that policy and oversight of research studies must contain safeguards to protect medical records and personal health information from misuse or unauthorized access. Without strong oversight, we do not believe this data can be gathered and used ethically.

Lastly, no government-funded research should occur without a wide-reaching stakeholder process that gives Autistic people the opportunity to participate in the design of the research and have input into research goals. Autistic-led involvement is essential to ensure that research efforts are ethical, relevant and grounded in lived experience.

We recognize the value and dignity of every person to participate fully in living a meaningful life of freedom, choice, love, purpose and joy. We affirm our shared commitment to building a society where Autistic people are fully included, respected and empowered to lead self-determined lives.

