

State of Vermont

House of Representatives



Montpelier, Vermont

House Resolution

H.R. 9

Offered by Representatives Burrows of West Windsor, Chapin of East Montpelier, LaMont of Morristown, Carris-Duncan of Whitingham, Casey of Montpelier, Coffin of Cavendish, Cole of Hartford, Cordes of Bristol, Dodge of Essex, Durfee of Shaftsbury, Graning of Jericho, Greer of Bennington, Harple of Glover, Harrison of Chittenden, Headrick of Burlington, Howard of Rutland City, Kleppner of Burlington, Krasnow of South Burlington, Labor of Morgan, McCann of Montpelier, McGill of Bridport, Mrowicki of Putney, Pezzo of Colchester, Priestley of Bradford, Rachelson of Burlington, Stevens of Waterbury, Sweeney of Shelburne, Tomlinson of Winooski, Torre of Moretown, and Wood of Waterbury

House resolution urging that all State agencies, departments, and offices protect the civil rights, medical confidentiality, and all aspects of personal privacy of Vermonters who have been diagnosed with autism in light of the Secretary of the U.S. Health and Human Services' recently announced plans to establish an autism research database and other databases related to autism

Whereas, the State of Vermont is fully committed to ensuring the enforcement of the rights of individuals with disabilities and the provision of inclusive services and person-centered systems of care, and

Whereas, individuals with autism contribute their talents, perspectives, and problem-solving abilities to strengthen Vermont's workforce; enrich families and communities; and advance innovation in science, technology, the arts, and beyond, and

Whereas, autism is a neurological difference, not a disease or an epidemic, and

Whereas, the rising autism identification rates, which trained clinicians and health care professionals are documenting, are attributable to improved diagnostic practices, greater awareness of autism, and expanded access to screening tools, and

Whereas, individuals with disabilities, including individuals with autism, are too often stigmatized and underestimated, and public policy should never diminish the diverse strengths and potential of these Vermonters, and

Whereas, the Secretary of the U.S. Department of Health and Human Services, Robert F. Kennedy Jr., has announced plans to establish a federal research database intended to be used to investigate the root causes of autism, and

Whereas, this new database will be a compilation of information derived from individuals' insurance claims; electronic medical records; and wearable devices, such as smart watches, and

Whereas, although this new database is no longer characterized as an "autism registry," as Secretary Kennedy and National Institutes of Health Director, Dr. Jay Bhattacharya, had previously announced, and despite public promises of personal and medical privacy, significant concerns remain regarding the potential use of Vermonters' sensitive, personally identifiable health care information without their specific and informed consent, and

Whereas, the Governor of the State of Illinois has issued Executive Order 2025-02 (the EO) to ensure that Illinois state officials fully comply with all applicable state and federal legal privacy protections in matters affecting the collection and use of information of persons being tested for, or who have been diagnosed with, autism, or in any database that now or may in the future exist that includes personal information related to autism; that the information not be collected, unless done so is strictly necessary for authorized purposes; and that the information not be disclosed outside state government except if one of the conditions listed in the EO is met, and

Whereas, it is imperative that Vermont officials are similarly vigilant in their protection of personal data being collected for any type of analysis or assessment related to autism, *now therefore be it*

Resolved by the House of Representatives:

That this legislative body urges that all State agencies, departments, and offices do everything in their power to protect the civil rights, medical confidentiality, and all aspects of personal privacy of Vermonters who have been diagnosed with autism, *and be it further*

Resolved: That the Clerk of the House be directed to send a copy of this resolution to the U.S. Secretary of Health and Human Services, the Director of the National Institutes of Health, the Vermont Congressional Delegation, the Vermont Secretary of Human Services, the Vermont Human Rights Commission, and the Governor.