ARTICLE

Peer Reviewed

Exploration of Mental Health Clinician Attitudes Towards a U.S. Federal Autism Registry

Chris Dabbs PhD, R.Psych, HSPP
University of Lethbridge
Alberta, Canada

Audrey Scaer PhD, LP
Eastern Michigan University
Michigan, USA

Abstract

The U.S. Department of Health and Human Services has been developing a real-world data platform (i.e. a medical registry) for people diagnosed with autism spectrum disorder to “research…the root causes of autism…” (U.S. HHS, 2025). Seven U.S. states already include autism spectrum disorder as a diagnosis of submission to state-wide medical databases. However, there is a dearth of research aiding in understanding provider attitudes towards interacting with extant (or proposed) medical autism registries. To better understand this phenomenon, we surveyed 62 mental health clinicians (psychologists, counselors, social workers, marriage and family therapists) to explore their perspectives and knowledge about autism registries. Our results indicated that over 70% of our participants opposed the creation of a national autism registry. Attitudinally, 85% percent of our participants strongly disagreed that autism is an epidemic and 78% disagreed with the need to find a cure for autism. Cure endorsement was inversely correlated with level of contact with autistic people. Participants highlighted ethical worries regarding autism registries, including fears of discrimination and worries about the historical precedence of registries. We discuss our participants’ perspectives in the context of current state database utility, provider knowledge and attitudes, and ethical concerns.

Key Words: autism policy, database ethics, clinician attitudes, medical autism registry

Introduction

On May 7th, 2025, the U.S. Department of Health and Human Services announced the creation of a Real-World Data Platform to advance research on chronic health conditions, with the initial mission to identify the “root causes of autism spectrum disorder” (para. 2). This proposed platform is planned to connect multiple data sources, including electronic health records, insurance claims, and data from electronic wearables, into a singular database with shared data usage agreements (Make

America Healthy Again Commission, 2025). This proposal sparked national news coverage and public commentary, with one petition in opposition by a purported caregiver of autistic children receiving nearly fifty-thousand signatures (Smith, 2025).

This current proposal for the creation of a governmental autism registry is not unique in its scope. The first multinational research collaboration, the International Collaboration for Autism Registry Epidemiology (iCARE), was established in 2013, and includes data-sharing between countries that have established national autism registries (Schendel et al., 2013). Within the United States, the Children's Health Act of 2000 established a centralized clearinghouse within the Centers for Disease Control and Prevention for collection and storage of data related to autism and other pervasive developmental disorders in partnership with the creation of regional centers. In conjunction with the passage of this national legislation, West Virginia was one of the first states to implement a statewide diagnostic registry (WV Autism Training Center, n.d.). According to the State of New Jersey Department of Health, state autism registries function to monitor prevalence, plan for policy and service provision, and facilitate connections between individuals and resources (2016).

The creation of medical registries engenders complex ethical considerations for individual and collective patient welfare. These considerations include limitations to informed consent, protections for privacy and confidentiality, the sensitivity of data collected (including genetic data), and minimization of potential harm — including the risks of compounding stigmatization and discrimination for vulnerable populations (Gliklich et al., 2020). Mariner (2007) argues that any disclosure of personal medical information for the purposes of governmental surveillance should be justified specifically and continuously for its violation of personal privacy, rather than justified generally for the promotion of ill-defined "public health" efforts. For mental health professionals who diagnose and serve autistic clients, the disclosure of clinical data for public health potentially impacts their clients and their profession.

The purpose of the present study is to utilize exploratory data and analysis to understand the knowledge and attitudes of mental health professionals towards the current proposal of the creation of a broadened, national medical registry of autistic people in the United States. We hope that this study will provide a provisional understanding of mental health professional attitudes regarding current developments that can be expanded upon by future research.

Method

Participant demographics

We recruited participants in the current study primarily via social media and targeted sampling of U.S. clinician email listservs (e.g., Division 17 of the American Psychological Association). Because we wanted to be as inclusive with respect to professional identity as possible, we permitted participants from a diverse spread of mental health professions, including psychology, counseling, social work, marriage and family therapy, psychiatry, and nursing alongside trainees in those professional fields.

Of our 62 participants, our demographics leaned predominantly doctoral, with 64.5% of our population being comprised of psychologists or psychologists in training (23 professionals; 17 psychology trainees). The remainder of participants (n = 22) were from the fields of counseling (n = 10; 9 professionals and 1 trainee), social work (n = 8), and couples and family therapy (n = 3). For our trainee participants, 50% of our population were in training year 3 or lower. Of our graduated professionals, 50% had been practicing for 6 or fewer years, while 18.2% had been practicing between 7 and 10 years. Around one-fifth (22.6%) of our professional sample reported being in practice for more than 10 years.

Alongside their professional identity and experience, we asked participants to estimate their level of autism-related clinical practice. Half of our sample estimated that 15% or fewer of their clientele were autistic. Approximately 18% of our participants estimated that 50% or more of their clientele were autistic. Most of our sample (69.4%) indicated that they do not diagnose autism spectrum disorder (ASD) in their practice and, of those who did report diagnosing ASD, approximately 84% rendered between 1 and 5 diagnoses in the previous year.

Procedure and analyses

The current project was approved by the corresponding author’s previous institution and data was collected between May 1 and May 14, 2025. The survey for the project was administered online via Qualtrics. All participants completed an informed consent process before accessing the survey. While participants were not monetarily compensated, they were informed of indirect benefits — including contributions to an under-researched area of autism practice perspective. The average time-to-complete the survey was 6 minutes and 50 seconds. Fifteen participants were cut from the final analyses due to incomplete data (final N = 62).

As an exploratory survey, the statements and questions we prompted were selected from existing measures of autism stigma via their foveal connection to the current autism registry zeitgeist. That is, we were interested in understanding perspectives related to commonly expressed talking points. For example, the current U.S. administration frequently uses the term "cure" when discussing the proposed outcomes of its autism registry efforts. Therefore, we utilized an item from an autism stigma measure to ask participants to rate their agreement with the phrase: "It is important for researchers and doctors to devote resources to genetic and biological research to find a cure for autism" (Kim, 2020). Similarly, the current administration has regularly used the term "epidemic" when discussing epidemiological rates of autism, so we selected an item from an autism stigma subscale of a neurodiversity attitudes scale to ask participants to rate their agreement with the phrase "autism is an epidemic" (VanDaalen et al., 2025).

Results

A series of frequency analyses, Friedman's tests of differences, and Pearson's correlations were utilized to explore the nature of our data, including participant knowledge and awareness about national and state autism registries and their general perspectives about the utility of autism registries.

Knowledge and Awareness

Most of our participants (~60%) reported moderate-to-substantial familiarity with current U.S. governmental proposals to create a national autism registry — 8% of our participants were unaware and learned of the intent through the current survey. While most of our participants rated moderate familiarity with national calls, of our eight participants practicing in states with existing autism registries, only two were aware of their existence. As expected, of the six practitioners unaware of their state autism registries, all six indicated they were unaware of their legal reporting requirements.

Autism and Registry Perspectives

Eighty-five percent of our participants strongly disagreed with the statement "autism is an epidemic" — 5% strongly agreed with the statement. Additionally, 78.3% of our participants somewhat or strongly disagreed with the statement "it is important for researchers and doctors to devote resources to genetic and biological research to find a cure for autism" — 11.7% of participants agreed somewhat (10%) or strongly (1.7%) to the statement.

A significant majority of our participants (~84%) rejected the notion that autism registries provide valuable epidemiological data that benefits public health planning and the provision of services with ~89% of our participants somewhat (12.9%) or strongly (75.8%) agreeing that autism registries may lead to increased autistic stigmatization. When asked to imagine what registry type might be the most beneficial, 71% indicated ‘no registry’ — 11.3% indicated that voluntary reporting with incentives (e.g., monetary governmental stipend) would be the most beneficial. A large minority of participants (43.5%) indicated that registry data should only be collected from patients themselves; other regularly endorsed sources were families (14.5%) and health care providers (~10%). A minority of participants endorsed the utility of medical record sources for registry data: governmental facilities (4.8%), private facilities (3.2%), lab testing (1.6%). Fifty-eight percent of participants indicated that data should be collected from no source (participants were allowed to select multiple options, so percentages may exceed 100%).

Participants were asked to rank their most significant ethical concerns and most important safeguards regarding autism registries (1 = most important). Results indicated significant differences in the rank-order of ethical concerns, $\chi^2(6) = 166.71$, $p < .001$. Mean ranks suggested that *discrimination* was perceived as the primary ethical concern (2.52) with *historical precedence (e.g., how registries have been used in the past)* as the secondary concern (2.85). Post-hoc Wilcoxon signed-rank tests showed that *historical precedence* was ranked significantly more important than all other concerns except *discrimination*. Similarly, results indicated significant difference in the rank-order of safeguarding measures, $\chi^2(8) = 160.43$, $p < .001$. Mean ranks suggested that *de-identification* measures were perceived as the primary concern (2.34) followed by *anti-discrimination protections* as the secondary concern (3.90). Post-hox Wilcoxon signed-rank tests showed that *de-identification* measures were ranked significantly more important than all other safeguards. All Friedman’s tests can be found in Table 1.

Autistic Contact and Disability

We asked participants about their level of personal contact with autistic people and their own disability statuses to gauge potential familiarity, exposure, and identity-based effects. A large majority of our sample (95.2%) had some current or historical contact with autistic people, including: having an autistic classmate (61.3%), employed alongside an autistic person (66.1%), being friends with an autistic person (74.2%), volunteering with an autistic person (30.6%), having an autistic family member

(53.2%), being in a romantic relationship with an autistic person (16.1%), being the primary caregiver for an autistic person (22.6%), and being part of the autistic community (19.4%). Approximately 32% of our participants identified as disabled, including disabilities such as: ADHD (19.4%), ASD (11.3%), health conditions (e.g., diabetes, HIV, arthritis; 16.1%), learning disabilities (1.6%), mobility disability (6.5%), and psychological disability (e.g. PTSD, major depressive disorder; 19.4%).

We conducted Pearson product-moment correlations to determine if autistic contact or disability status were correlated with responses to questions concerning an autism "epidemic" or "cure." We created autistic contact and disability status variables by summing categories of contact and disability (with higher totals indicating more contact with autistic persons and increased intersecting disability statuses). Neither variable (contact nor disability status) was significantly correlated with perceptions of autism as an epidemic nor was disability status significantly correlated with perceptions of a need to cure autism. However, autistic contact level was significantly inversely correlated with perceptions of need for an autism cure (r = -0.28, p = .03).

Discussion

Our exploratory analyses reveal a general attitudinal trend across our mental health clinician participants which included low endorsement of three variables: a) autism as an epidemic, b) a need to cure autism, and c) the utility of a national autism database. In addition, though some U.S. States (Delaware, Indiana, New Jersey, North Dakota, Rhode Island, Utah, and West Virgina) already require providers to report diagnoses of autism spectrum disorder to a real-world data platform (State of New Jersey Department of Health, 2016), only 75% of our participants living in those States were privy to the existence of these databases in the context of autism spectrum disorder.

While an exploration of provider state-based registry utility is beyond the scope of this report, there is a precedent in the State of New Hampshire for legislative criticism of autism registries. In 2024, the New Hampshire Health, Human Services, and Elderly Affairs committee sought public feedback on their autism registry, established in 2006. Primary criticism of the registry included: patient privacy concerns, concerns of accuracy, lack of provider utility, concerns with dynamic diagnostic criteria, lack of state supports for autistic adults, and lack of pragmatic and beneficial use of the aggregated data beyond what is already done in standard pediatric care (NH House of Representatives Committee Streaming, 2024). In defense of the New Hampshire autism registry, a proponent cited utility of the aggregate registry data for the U.S. Department of Education. However, the current U.S. administration seeks to close the Department of Education, thus further reducing the utility of state autism registries for educational planning (Executive Order No. 14242). Based on these criticisms, New Hampshire chose to entirely repeal their autism registry (An Act Relative to the Autism Registry, 2024).

The concerns highlighted by opponents to the New Hampshire registry mirror the ethical and safeguarding concerns of both our participants and the larger body of literature regarding ethical concerns with respect to research focused on prevention (i.e. cure). For example, Botha and Cage (2022) identified that medicalized autistic narratives (e.g. those often used in autism registry research) predict higher levels of ableism — like the discrimination that our participants indicated as their most-endorsed ethical concern. In addition, research in the autism community (which included professionals working with autistic people) has identified concerns of research focusing heavily on “curing” autism rather than supporting autistic people and a lack of consideration for community-led autistic decision making on research priorities (Harr et al., 2024; Pugsley et al., 2025). A large majority of our participants, over half of whom were in the greater autism community, indicated opposition to the idea that autism required a “cure” and, likewise, opposed the utility of autism registries writ large. These findings underscore the important allyship by mental health professionals and their corresponding professional organizations who recognize misalignments between the research priorities of the autistic community and current priorities of the U.S. administration.

References

An Act Relative to the Autism Registry, NH HB1615, Chapter 78 (2024). https://gc.nh.gov/bill_status/legacy/bs2016/billText.aspx?sy=2024&id=1515&txtFormat=html

Botha, M., & Cage, E. (2022). "Autism research is in crisis": A mixed method study of researcher's constructions of autistic people and autism research. *Frontiers in Psychology*, *13*, 1050897. https://doi.org/10.3389/fpsyg.2022.1050897

Children's Health Act of 2000, H.R.4365, 106th Cong. (2000). https://www.congress.gov/bill/106th-congress/house-bill/4365/text

Executive Order No. 14242, 90 FR 13679, (2025). https://www.govinfo.gov/content/pkg/FR-2025-03-25/pdf/2025-05213.pdf

Gliklich, R. E., Leavy, M. B., & Dreyer, N. A. (2020). Principles of registry ethics, data ownership, and privacy. In *Registries for Evaluating Patient Outcomes: A User's Guide [Internet]. 4th edition.* Agency for Healthcare Research and Quality (US).

Haar, T., Brownlow, C., Hall, G., Heyworth, M., Lawson, W., Poulsen, R., Reinisch, T., & Pellicano, E. (2025). 'We have so much to offer': Community members' perspectives on autism research. *Autism: the International Journal of Research and Practice*, *29*(9), 2254–2267. https://doi.org/10.1177/13623613241248713

Kim, S. Y. (2020). The development and pilot-testing of the autism attitude acceptance scale: An instrument measuring autism acceptance. *Autism in Adulthood, 2*(3), 204-215. https://doi.org/10.1089/aut.2019.0066

Make America Healthy Again Commission. (2025, September 9). *Strategy report: Make our children healthy again.* https://www.hhs.gov/press-room/maha-commission-report-childhood-disease-strategy.html

Mariner, W. K. (2007). Mission creep: public health surveillance and medical privacy. *Boston University Law Review*, 87(2), 347. https://scholarship.law.bu.edu/faculty_scholarship/360

New Hampshire House of Representatives Committee Streaming. (2024, Feb. 14). *House Health, Human Services and Elderly Affairs (02/14/2024)* [Video]. YouTube. https://www.youtube.com/live/Ohv_-0m_OvY

Pugsley, K., Siryj, N., Alvares, G. A., Baxter, E., Bellgrove, M. A., Chau, T., ... & Johnson, B. P. (2025). "We need community-centred, strongly ethical genetic research": A qualitative investigation of community attitudes toward autism genetics. A*utism in Adulthood. Advance online publication*. http://doi.org/10.1177/25739581251370568

Schendel, D. E., Bresnahan, M., Carter, K. W., Francis, R. W., Gissler, M., Grønborg, T. K., ... & Susser, E. (2013). The International Collaboration for Autism Registry Epidemiology (iCARE): multinational registry-based investigations of autism risk factors and trends. *Journal of Autism and Developmental Disorders, 43*(11), 2650-2663. https://doi.org/10.1007/s10803-013-1815-x

An Act Relative to the Autism Registry, NH HB1615, Chapter 78 (2024). https://gc.nh.gov/bill_status/legacy/bs2016/billText.aspx?sy=2024&id=1515&txtFormat=html

Smith, R. (2025). Stop the national autism registry: Protect our children's privacy and human rights. *Change.org.* https://www.change.org/p/stop-the-national-autism-registry-protect-our-children-s-privacy-and-human-rights

State of New Jersey, Department of Health. (2016). A comparison of state autism registries: New Jersey and beyond. Autism Registry Publications. https://www.nj.gov/health/fhs/autism/documents/2016%20overview%20of%20States%20Autism%20Registries%20Brief.pdf

U.S. Department of Health and Human Services. (2025, May 7). *NIH, CMS partner to advance understanding of autism through secure access to select Medicare and Medicaid data*. [Press release]. https://www.hhs.gov/press-room/nih-cms-partner-to-research-root-causes-of-autism.html

VanDaalen, R. A., Dillon, F. R., Santos, C. E., & Capielo Rosario, C. (2025). Development and initial validation of the autism and neurodiversity attitudes scale. *Autism in Adulthood, 7*(1), 39-51. https://doi.org/10.1089/aut.2023.0090

West Virginia Autism Training Center. (n.d.). *West Virginia Autism Spectrum Disorder Registry.* Marshall University. https://www.marshall.edu/atc/wvasd-registry/

Acknowledgements: None

Competing Interests: The authors declare a non-financial conflict of interest in that they both regularly work within the neurodiversity movement and from a neurodiversity-affirming paradigm.

Funding and Support: The authors received no financial support for the research and authorship.

Data availability: The datasets generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.

Address for Correspondence: chris.dabbs@uleth.ca

Publication Date: April 15, 2026

Table 1.

Friedman's tests of differences in ranked ethical concerns and registry safeguard provision.

	Concern	Mean Rank	χ^2	*p*
Ethical	Medical information privacy	3.73		
	Informed consent	4.18		
	Discrimination	2.52		
	Autonomy	4.40		
	Tracking and surveillance	3.42		
	Historical precedent	2.85		
	Other	6.90		
Overall test			166.71	<.001
Safeguarding	De-identification	2.34		
	Encryption and other data security	4.50		
	Data access controls	5.61		
	Informed consent	4.53		
	Limitations on purposes of collected data	5.02		
	Transparency in data use	4.68		
	Ability to access own data	6.76		
	Anti-discrimination protection	3.90		
	Sunset provisions	7.66		
Overall Test			160.43	<.001