May 12, 2025

The Honorable Robert F. Kennedy, Jr.
Secretary
Department of Health and Human Services
Room 120F, Hubert H. Humphrey Building
200 Independence Avenue, SW
Washington, DC 20201

Dear Secretary Kennedy:

The below-signed disability rights, civil rights, and public health organizations and professionals write to raise our significant concerns about the National Institute of Health (NIH) proposal to create a national autism "registry." The proposal, released as part of an April 21 presentation by NIH Director Jay Bhattacharya, detailed the development of a "real-world data platform" that would serve as the basis for "developing national disease registries, including a new one for autism."[1] Although the Department of Health and Human Services (HHS) has since stated it is not creating an "autism registry," the larger platform's unclear purpose and potential for abuse necessitates that HHS and NIH engage with disability and civil rights advocates and implement fundamental safeguards.

Data collection and sharing can pose serious risks. Some data collection enables researchers and policymakers to better understand and meet the needs of people with disabilities, while other types of data collection can and have led to increased surveillance, stigmatization, and marginalization. Disabled people in the United States have a long and troubled history with governmental efforts to find and track disability for the purpose of eliminating it.[2] The lack of clarity about what NIH specifically intends to do has led to immense concern among autistic people, family members, privacy advocates, and researchers.

HHS and NIH's failure to engage with autistic people and autistic advocates has exacerbated this lack of clarity. Under previous administrations led by both Democrats and Republicans, autistic people, advocates, and other organizations had direct lines of communication with autism policy experts within HHS. That communication enabled autistic people and advocates to give feedback, raise concerns, and ask questions. If autistic people, advocates, and researchers had the opportunity to provide input into Dr. Bhattacharya's proposal, we would have urged the administration to clarify important details, such as whether they planned to collect personally identifiable information, how

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[1] Dr. Jay Bhattacharya, Director, National Institutes of Health, *NIH Director's Update* (Apr. 21, 2025), https://dpcpsi.nih.gov/sites/default/files/2025-04/Council-of-Councils-04.21.25-Director-Update.pdf; Alexander Tin, *Health Agencies "Not Creating an Autism Registry," Official Says, Contradicting NIH Director*, CBS News (Apr. 25, 2025), https://www.cbsnews.com/news/health-agencies-not-creating-autism-registry-hhs-nih.

[2] *On A 'Eugenics Registry,' A Record Of California's Thousands Of Sterilizations*, NPR (Dec. 18, 2016), https://www.npr.org/2016/12/18/505000554/on-a-eugenics-registry-a-record-of-californias-thousands-of-sterilizations.

they would go about collecting data they proposed to gather from sources like wearables, and how this data would be used and secured.[3]

Unfortunately, disengagement with autistic people and advocates has been emblematic of HHS's approach to autism policy under this administration: it has kept autistic people and leading autism organizations from the discussion. Autism advocates have been pointedly denied the opportunity to weigh in on our community's research priorities. NIH's failure to engage the larger autism community before launching its "real-world data platform" is deeply troubling and a missed opportunity for autism support.

We continue to have many unanswered questions about the data platform and the study (if not a "registry") of autism that it will support. HHS must answer essential questions as soon as possible such as what data it will collect, what sources it will rely on, and how it will deidentify and secure the data. Many key research projects rely on data from multiple sources,[4] and where the data's collection, use, and retention are accompanied by sufficient safeguards, the research can provide meaningful benefits while reducing its risks, as has been well established in medical research for decades.[5] Research to better support autistic people is extremely valuable and should be continued; that work, however, is only possible through the use of health data with meaningful privacy protections. Failure to provide those protections may chill individuals' willingness to participate in research, seek services, or even openly identify as autistic.

To establish trust in the "real-world data platform" and the projects it supports, NIH and HHS must take three key steps:

- **Engage with disability rights, privacy, and civil rights advocates.** Meaningful communication with autistic people and advocates is essential to ensuring that data-driven projects are rooted in trust. People with autism and their families can help shape HHS projects in meaningful ways based on their lived experience, and advocates with expertise in disability rights, privacy, and civil rights can advise on establishing proper policy and technical safeguards to protect privacy and civil rights. Engagement will also facilitate transparency around the collection and ultimate use of data and help ensure that the autism community is invested in the work.

- **Establish fundamental privacy safeguards.** Building trust in data collection and use requires establishing safeguards that help prevent misuse and abuse of the

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[3] NIH is actively establishing the infrastructure for its data platform and autism study, including by implementing data sharing with the Centers for Medicare and Medicaid Services (CMS). Although NIH and CMS have stated the data sharing will be "privacy and security compliant," it has not provided details of that arrangement to the autism community. *See NIH, CMS Partner to Advance Understanding of Autism Through Secure Access to Select Medicare and Medicaid Data,* Nat'l Inst. Health (May 7, 2025), https://www.nih.gov/news-events/news-releases/nih-cms-partner-advance-understanding-autism-through-secure-access-select-medicare-medicaid-data.

[4] *E.g.*, Administration for Community Living, Developmental Disabilities Projects of National Significance (2024), https://acl.gov/sites/default/files/programs/2025-01/projects-natl-significance_factsheet-acl.pdf.

[5] *E.g.*, 42 C.F.R. §§ 164.306 –164.316; *id.* §§ 164.502–164.514.

data. Federal data collection and use is rooted in key principles established in policies such as the Fair Information Practice Principles[6] and the Office of Management and Budget's Circular A-130.[7] Data must be collected for a specific purpose and its use limited to that purpose. Agencies should ensure the quality and integrity of the data, foster public transparency, and obtain individual consent to share personally identifiable information or to use it for any purpose beyond those necessary to deliver services. Any NIH research or data platform must comply with these essential requirements.

- **Ensure that the data platform helps, not hurts, autistic people and people with disabilities.** The ultimate goals of the NIH's data platform should be to advance the well-being of autistic people, people with disabilities, and the public health — while minimizing potential harms. This can be achieved by ensuring that studies and research rely on the sound scientific practices that are at the heart of any "gold-standard research." Similarly, engaging with affected communities and establishing privacy safeguards, such as conducting privacy impact assessments under the e-Government Act,[8] can help identify potential harms early on. Ultimately, however, it is up to NIH and HHS to assess its proposal, before deploying it, to ensure that its benefits outweigh its risks.

Trust and collaboration in NIH's data platform is essential. We urge NIH and HHS to revisit its approach to its "real-world data platform" to ensure that impacted communities are consulted, that the platform is accompanied by privacy safeguards, and that the platform furthers the wellbeing of autistic people, people with disabilities, and the public health.

Please feel free to reach out to Larkin Taylor-Parker (ltaylorparker@autisticadvocacy.org) and Greg Robinson (grobinson@asan.org) at the Autistic Self Advocacy Network and Cody Venzke (cvenzke@aclu.org) and Vania Leveille (vleveille@aclu.org) at the American Civil Liberties Union with any questions.

Sincerely,

Access Living
Advocacy for Principled Action in Government
Alliance For TransYouth Rights
American Civil Liberties Union
American Music Therapy Association
American Therapeutic Recreation Association
Autism Society of America
Autistic People of Color Fund
Autistic Women & Nonbinary Network
Bronx Developmental Parents Association, a Chapter of The Arc New York

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[6] *Fair Information Practice Principles (FIPPs)*, Federal Privacy Council (2022), https://www.fpc.gov/resources/fipps.
[7] Office of Management and Budget, Circular No. A-130 (2016), https://www.cio.gov/policies-and-priorities/circular-a-130.
[8] 44 U.S.C. § 3501 note.

Brooklyn Center for Independence of the Disabled
Caring Across Generations
Center for Democracy & Technology
Center for Law and Social Policy (CLASP)
Center for Public Representation
CenterLink: The Community of LGBTQ Centers
Changing Perspectives
CIDA
Coalition for Asian American Children and Families
Coalition on Human Needs
CommunicationFIRST
Consumer Federation of America
CUNY School of Law, Disability Rights and Social Justice Clinic
Defending Rights & Dissent
Demand Progress Education Fund
Robert D. Dinerstein, Professor of Law Emeritus, American University Washington College of Law*
Disability Belongs
Disability Law Center of Utah
Disability Rights Arizona
Disability Rights Arizona
Disability Rights California
Disability Rights Center - NH
Disability Rights Florida
Disability Rights Iowa
Disability Rights North Carolina
Disability Rights South Carolina
Disability Rights Tennessee
Easterseals
Electronic Frontier Foundation
Electronic Privacy Information Center
Empowering Pacific Islander Communities (EPIC)
Fight for the Future
Hertog Education Law PC
IEC (Institute for Exceptional Care)
Integrated Community Collaborative
Inter Agency Council of Developmental Disabilities Agencies, Inc.
Iowa Developmental Disabilities Council
Japanese American Citizens League
Law Office of Kimberly Spire-Oh
Long Island Center for Independent Living, Inc. (LICIL)
National Advocacy Center of the Sisters of the Good Shepherd
National Association for Rights Protection and Advocacy
National Association of Councils on Developmental Disabilities
National Disability Rights Network (NDRN)
National Disabled Legal Professionals Association
National Down Syndrome Congress
National Health Law Program
National LGBTQI+ Cancer Network

National PLAN Alliance
Native American Disability Law Center
Nevada Disability Advocacy & Law Center
New America's Open Technology Institute
New York Alliance for Developmental Disabilities
North Dakota Protection & Advocacy Project
NYC FAIR Family Advocacy and Information Resource
Open MIC
PASILC
Primary Care Development Corporation
S.T.O.P. - The Surveillance Technology Oversight Project
South Asian Public Health Association (SAPHA)
Southern Tier ADAPT
Southern Tier Independence Center
Suffolk Progressives
The Advocacy Institute
The Autism Connection of PA
The Institute for Health Research & Policy at Whitman-Walker
The Leadership Conference on Civil and Human Rights
TransFamily Support Services
Treatment Action Group
United Church of Christ
United Church of Christ Media Justice Ministry
Utah Disability Advocacy Network (UDAN)

*For identification purposes only

Cc: Dr. Jay Bhattacharya, Director, National Institutes of Health
Dr. Mehmet Oz, Director, Centers for Medicare and Medicaid Services
Heather Melanson, Chief of Staff, Department of Health & Human Service
Sean Keveney, Acting General Counsel, Department of Health & Human Services
Stefanie Spear, Principal Deputy Chief of Staff & Senior Counselor, Department of Health & Human Service