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Dangers of the NIH-RFK Jr. Autism Research Initiative

The proposal by the National Institutes of Health to centralize sensitive health data—including pharmacy records, lab results, genomic profiles, insurance claims, and real-time biometric data from wearables, for external autism research raises profound concerns about ethics, civil liberties, and the treatment of neurodivergent individuals. This effort, being advanced under the direction of Secretary Robert F. Kennedy Jr., echoes alarming historical and fictional precedents of government surveillance and profiling under the guise of scientific progress or national interest.

In particular, this initiative bears disturbing resemblance to the fictional “Flight 828 Registry” from NBC’s television series *Manifest*. In the show, passengers who mysteriously returned after a five-year disappearance were placed in a government database, subjected to constant surveillance, medical experimentation, and arbitrary detention. The registry, originally intended to track and study these individuals, quickly evolved into a tool of control and dehumanization, justified by claims of public interest and scientific inquiry. Although *Manifest* is fiction, it serves as a cautionary allegory about the ease with which governments can overstep, especially when dealing with people perceived as “different,” “anomalous,” or “in need of explanation.”

In a similar way, this real-world NIH initiative threatens to pathologize and profile autistic individuals through the creation of a national autism registry. This registry, when combined with other data streams and made available to outside researchers selected without community input or rigorous accountability, risks becoming a surveillance apparatus cloaked in medical language. Such a system may be used to justify interventions that prioritize normalization over support, or even policies that restrict the rights and freedoms of autistic individuals under the pretense of care.

Historically, we have seen the devastating consequences of mass registries and government tracking. From the internment of Japanese Americans during World War II, to the surveillance of activists during the civil rights era, to the current threats posed by predictive policing and biometric data misuse, the pattern is clear: when marginalized populations are cataloged, studied, and monitored without their consent, it sets the stage for discrimination, loss of agency, and state-sanctioned harm.

Kennedy’s repeated characterization of autism as a “preventable disease” further positions this initiative not as a neutral scientific endeavor, but as a crusade to identify and eliminate neurodevelopmental differences. This framing is reminiscent of past efforts to institutionalize or

sterilize individuals deemed “unfit,” as seen in the eugenics movement—efforts that were backed by seemingly reputable research and state support at the time. The idea that such a registry could be integrated into “real-time health monitoring” of Americans reveals a chilling disregard for the right to privacy and bodily autonomy.

While the NIH asserts that researchers will not be able to download the data and that protections will be in place, the creation of such a vast, integrated, and permanent repository of personal information inherently increases the risk of misuse—whether by governments, corporations, or others with ideological agendas. Once a registry of this nature exists, it becomes difficult to control its use or limit its consequences.

This initiative must be opposed not only on ethical and scientific grounds, but also on the basis of civil liberties. We cannot allow the path forward for autism research to be paved by the collection and classification of individuals as though they are problems to be solved or diseases to be eradicated. A just society invests in acceptance, support, and empowerment—not registries and reductionism.

We must learn from both fiction and history: when we allow fear or bias to drive the architecture of our health policy, we risk building systems that imprison the very people they claim to help.

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