## ASAN Gravely Concerned by Administration’s Plans for Autistic People’s Medical Data

- **4/24/25: Clarification**
  As of late this afternoon, HHS has released new information about the proposed autism database that we discussed in the statement below. We are in the process of preparing a response to that information, which will come out tomorrow. In the meantime, we would like to clarify our existing statement to address questions we have gotten from the community about ASAN’s stance on research and how this database would affect them personally.

At present, it is unclear what data will be included in the announced autism database—what the sources of the data will be, how they will be connected, and, crucially, **whether any Personally Identifiable Information (PII) about autistic people will be provided to researchers.** If all PII is actually stripped out of the database, and individuals cannot be identified, then it is normal practice to distribute that information to researchers without individuals’ specific consent. Autistic people’s privacy would likely not be endangered by deidentified data being shared with researchers. Except when we feel the research is harmful for other reasons, ASAN *supports* the use of large federal healthcare datasets for research purposes, including ones that link information from multiple sources, *provided that that data is thoroughly and carefully deidentified*

On the other hand, if individuals are identifiable based on the provided information, then serious concerns about privacy are very much warranted. PII should not be shared with researchers without rigorous consent procedures and additional privacy protections. Without more information about how this database will work, which NIH has yet to provide to our community, we will continue to have serious concerns about privacy for autistic people who are included in this database. This administration has already demonstrated that it does not prioritize the privacy of vulnerable communities. Disclosure of autistic people’s PII without their consent, whether deliberately or through carelessness, could have a host of negative consequences, from making them the targets of phony cure scams, to exposing them to harassment or discrimination. At present, we have not seen evidence that PII will be disclosed in this database, but we will continue to push for more information to make sure our community’s privacy is safeguarded.

We also wanted to address the fears we are seeing in the community around how this database could be employed against our community in areas beyond research. We recognize that the current climate – fostered in large part by RFK Jr. himself in his recent remarks – has caused a lot of understandable fear in our community. However, there is no indication at this point that this database is going to be used to target individual autistic people or "round up" members of our community. If any information comes out to suggest that they are even moving in that direction, you will hear loud and clear from us about it, and we will be on the front lines fighting it.

**Original statement follows:**

ASAN is gravely concerned by Health and Human Services (HHS) Secretary Robert F. Kennedy Jr.'s (RFK Jr.) reported plans to establish a "registry" of autistic people and to hand over sensitive medical data about autistic people to unnamed researchers, likely without their consent. At present, so little information has been released about this plan that basic questions about how it will work remain unanswered. For example, we do not know how autistic people will be identified, whether personally identifying information will be culled from the collected data, what confidentiality protections there will be, or whether people will receive any notice that their information is being used, or have the opportunity to opt out of the collection of personal data. It is also unclear exactly what data sources will be part of the study, and how they will be integrated; CBS' reporting indicates that data sources will include not only medical billing data, but individuals' prescription records and data from personal devices like smartwatches. ASAN will insist that the administration actually answer those questions. However, given not only this administration's deplorable, eugenic rhetoric about autism, but its demonstrated disregard for basic standards of scientific evidence, there is every reason to believe that this data will be misused in troubling and dangerous ways.

We have already seen that RFK Jr. cannot be trusted to ensure that the researchers he invites to this work follow basic scientific ethics or professional best practices. David Geier, his choice to head the announced "study" into vaccines and autism, was fined for practicing medicine without a license after he provided dangerous and ineffective treatments to autistic children. For one of his "studies" into vaccines and autism, instead of seeking approval from an institutional review board (IRB) — an outside oversight group that all medical research on human subjects must have to ensure they are conducted ethically and do not endanger patients, and which require even greater scrutiny to experiments on vulnerable populations such as children — he and his father created a sham IRB made up of their family members and business associates. We don't know yet whether Mr. Geier would be one of the researchers who would be handed autistic people's private medical information, but someone like him could do serious damage if allowed access to this information.

While National Institutes of Health Director Bhattacharya promised “state of the art protections” for confidentiality, we’ve also seen this administration repeatedly misuse Americans’ data for its own ends, such as giving DOGE access to sensitive treasury data and tax records that were supposed to be kept private. The administration’s assurances ring hollow because we see them actively stripping privacy protections from some vulnerable, disfavored groups, and encouraging the public to further violate the medical privacy of others.

In order to be done ethically and safely, especially if any information is at all personally identifiable, research that brings together this amount of medical data about individuals must be conducted with the express, informed consent of the participants. For the types of research seemingly being proposed, informed consent isn’t a one-off request. The sort of data collection RFK envisions can only be done ethically with thorough consent practices that apply to each type of collection. For example, the Framingham heart study, a long-running comprehensive longitudinal health study that is similarly comprehensive, has had rigorous patient consent policies for every single person covered by their dataset, including repeatedly getting permission before every visit since 1971, regular presentations to participants on what research is being done and why, and annual review by an outside Institutional Review Board to make sure that the research is proceeding ethically. RFK Jr. has not proposed any of this. There is no indication that autistic people whose data is being taken would be afforded any say in whether their data is used or what it is used for. This raises significant moral, legal, and practical concerns. People have a right to decide what is done with data about their health. Unethical science is bad science.

Medical data can also easily be manipulated by unscrupulous researchers to create the appearance of causation where it does not exist. This has already happened this year with an anti-vaccine “study” about autism that RFK Jr. approvingly cited during his confirmation hearing. The study, which was not published in a reputable scientific journal and did not go through peer review, used Medicaid data from Florida to show that children who had doctors visits to receive vaccinations were statistically more likely to also have doctors visits to receive care for autism. The authors claimed that this demonstrated that getting vaccinated could cause autism. **All this proved is that parents who take their children to the doctor are more likely to both get their children vaccinated and to have their children evaluated for autism, and to get them care if they are autistic.** Handing over huge amounts of data to people like these researchers would increase their ability to mislead the public by generating phony evidence for RFK’s predetermined conclusion: a link between vaccination and autism that real scientific studies have disproved over and over and over again.

These actions have parallels to past events. This country (as well as others) has a history of eugenics that resulted in heavy-handed governmental intervention in disabled people's lives. This brought about forced sterilization and forced institutionalization. Forced institutionalization, which kept disabled people out of sight and out of mind, laid the groundwork for the widespread use of people with disabilities as unconsenting subjects for unethical research. This included having children unknowingly ingest radiation and intentional infection of contagious diseases during the 20th century. More recently, it has included David Geier's unethical and illegal experiments on autistic children in the 2000s and the Glenwood Resource Center (a state-run institution in Iowa) which was found by the DOJ in 2020 to have run human experiments. We are certainly not the only community that has been subjected to unethical experimentation. People of color, such as Black, Latino, Filipino and indigenous communities, have also faced these kinds of harms. The reason why we have robust protections regarding informed consent today is because of advocates who, after centuries of suffering caused by unethical research, sought to prevent further unethical experimentation.

Members of this administration have repeatedly used eugenic language to talk about people with disabilities — for example, Trump's alleged comments that disabled people "should just die," RFK Jr.'s devaluation of autistic lives, and Elon Musk's public support for eugenics. This makes the administration seem like a particularly untrustworthy locus for a registry to track autistic people. The disability community, and many other marginalized communities, have reasonable fears, based in both historical events and in current policy pursued by the administration, of any attempts to create lists of marginalized people.

The Trump administration is once again trampling our civil rights in service of their own agenda. ASAN is dedicated to fighting for ethical autism research that reflects the needs of autistic people, and dedicated to defending the civil rights of our community and many others. We will pursue multiple avenues to demand answers from the government about this study and take action to protect our privacy.