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Ohio Senate Health Committee
Interested Party Testimony, HB 96
May 14, 2025

Thank you for the opportunity to provide testimony today, Chairman Huffman, Vice Chair Johnson, Ranking Member Antonio, and members of the Senate Health Committee. My name is Georgie Elson, and I am an Ohio resident deeply concerned about the changes to abortion reporting requirements and the public facing abortion dashboard that has been snuck into the budget bill, HB 96. I urge this committee to remove this portion of the bill from the Senate version of the budget due to its serious implications for receiving healthcare, patient privacy, public health policy, and reproductive rights in our state.

As an individual with multiple disabilities, including Autism, I find these registries and databases that take individuals private health information, without their consent, and share them to the wider public, to be dangerous to every resident in our country and state. These practices are a slippery slope that should concern us all.

HB 96 would expand the information required in abortion reporting and mandate the creation of a **public-facing** electronic dashboard updated monthly. While the bill claims to maintain patient anonymity, the level of detail it requires—particularly when combined (zip code, state of residence, age, number of previous abortions, and minor status)—raises significant risks of re-identification, especially in smaller communities and rural areas. Given the heated rhetoric that now surrounds abortion, I fear this database will lead to more physical and emotional violence towards women and may easily directly threaten their physical safety. Further, these provisions also undermine the core principle of medical confidentiality and may deter individuals from seeking timely reproductive care out of fear of exposure or stigma.

Additionally, the bill's requirement to sort abortion data by age brackets and prior abortion history adds a judgmental and invasive dimension to public health reporting. These categories are not medically necessary and appear to serve ideological rather than scientific purposes. Reproductive healthcare decisions are deeply personal and should not be reduced to demographic tallies for political scrutiny.

The monthly publication of such detailed information also raises ethical and logistical concerns. A real-time public abortion database, regardless of intentions, could become a tool for harassment, intimidation, or misinformation. Ohioans deserve policies that protect health, not legislation that threatens their safety and privacy.

Protecting medical privacy is vital because it safeguards individuals' dignity, autonomy, and trust in the healthcare system. Health information is deeply personal and can affect every aspect of a person's life—from their employment and insurance status to social relationships and psychological well-being.

The ways in which involuntary collection of private medical information, registries and databases can cause harm:

1. Autonomy, Consent, & Trust in Healthcare: Patients have the right to control who knows about their medical conditions. Without this control, they may be less likely to seek care, especially for stigmatized conditions such as abortion, mental illness, autism, or substance use disorders. To take this a step further, confidentiality is *the key* to fostering actual open communication between patients and providers. [*Let's be honest, if you knew your doctor was going to publish your private health information all over the internet, would you still feel comfortable telling him, that you've tried absolutely everything and you still can't get it up?*] But on a more serious note, if patients fear their information won't be kept private, they may withhold important details, undermining diagnosis and deter them from seeking care that could be lifesaving.
2. Discrimination and Stigma: Disclosure of certain medical conditions—especially without consent—can lead to social stigma, loss of employment, housing discrimination, or even targeted violence.
3. Chilling Effect on Public Health: If people end up avoiding testing or treatment, because they know they will be involuntarily registered or electronically dashboarded, this could severely undermine public health efforts and spread certain diseases further.
4. Legal and Ethical Principles: Medical privacy is protected by laws like HIPAA in the U.S. and upheld by medical ethics. Breaching it without compelling justification violates both. HIPAA was designed not only to establish national standards for the protection of health information, but also to improve the portability and continuity of health insurance coverage, and to reduce healthcare fraud and abuse. In other words, it is not a law that we would want to weaken or undermine, as it has other important protections to it.
5. Security Risks: Large centralized medical databases are high-value targets for hackers. A breach could expose sensitive information about vulnerable individuals.
6. High Potential for Abuse: Such registries or dashboards can be misused by employers, insurers, or government agencies, leading to discrimination, surveillance, political targeting or worse - as is commonly seen in other authoritarian countries. The creation of registries is how the genocide against disabled individuals, children and adults alike, started in Nazi Germany.
7. No Clear Public Health Benefit: There is no scientific or ethical justification for a mandatory registry. Medical research does not require involuntary or identifiable data collection.

Public health reporting should always be driven by evidence-based goals: improving outcomes, expanding access, and safeguarding communities. HB 96 does none of these. Instead, it places a chilling burden on patients and providers, while offering little in terms of meaningful public health benefits.

I would like to circle back to how the registration of children, and eventually adults, with disabilities led to their genocide, and later the mass genocide of other types of stigmatized individuals. It really did all start with a registry. (1) There was the creation of “The Reich Committee for the Scientific Treatment of Severe Hereditary & Congenital Diseases,” who knew their mission was murder, but were instructed to hide and lie about that to get physicians and midwives to fill out questionnaires naming the children they knew of, that had these disabilities

(2). The Committee told them it was to “Clarify certain scientific questions” and conveniently left out their true intention of mass murder (2).

This is what I mean when I say it is a slippery slope. The role back of privacy protections and creation of medical registries may look innocent enough now, but a lot can change in 3, 5, or 10 years. Put bluntly, we should not be creating a hit list that future individuals with evil intentions could use to fulfill their own violent fantasies.

Similarly, now we have a federal government taking the private health information of individuals with autism who are on Medicare or Medicaid without our consent(3), to supposedly find “the root causes of autism(3)” to “Make America Healthy Again(4),” and to deal with the “dire threat to the American people and our way of life(4),” that these conditions supposedly cause. The same executive order establishes “The President’s Make America Healthy Again Commission (4)” and talks about “adding powerful new solutions that will end chronic childhood disease (4).” As someone with Autism and multiple genetic disabilities that present in childhood, I want to know what happens when they realize that they cannot end all chronic childhood disease? What happens when they realize what autism research has been saying this whole time; When the realize that autism and many other such chronic childhood disorders are actually genetic and have no cure? When they realize diet and exercise can’t rid us of that “dire threat? (4)”

When the president says that you and your disability is a “dire threat to the American people and our way of life, (4)” and the Secretary of Health and Human Services floats sending individuals, **and children**, with certain conditions to Wellness camps (5), and the Administrator of The Centers for Medicare & Medicaid Services is saying things like, “70% of the money we spend is on chronic illness and we are not getting our money’s worth” and that “it’s your patriotic duty to be as healthy as you can (6),” we are already heading down a dark path. Such statements promote eugenics. I hope you can see how this kind of rhetoric, and these kinds of policies, could quickly lead to a repeat of some of our darkest histories as human beings.

At this point in time, as mass surveillance capabilities are skyrocketing, the federal government is creating an autism registry to try to find the cause that has already been found, and the head of Medicare & Medicaid services is spouting eugenist language like it’s the most natural thing in the world, I ask of you, our elected State Senators, and I ask of our other other State Representatives, to learn how to protect your constituents from these harms, instead of perpetuating them further.

How States Can Protect Citizens

1. Pass State-Level Data Privacy Laws:
 - Enact laws that explicitly ban the involuntary collection of personal health data without informed consent, including registries of medical or neurological conditions.
2. Strengthen Informed Consent Requirements:

- Require any registry or database to obtain explicit, informed, and revocable consent from patients or guardians.
- 3. Enforce HIPAA and Expand State Protections:
 - Work with federal authorities to enforce HIPAA and fill gaps with state-specific legislation (e.g., California's CCPA offers additional protections).
- 4. Ban Discriminatory Registries:
 - Make it illegal to create or use health registries for discriminatory purposes, including employment, education, housing, or public services.
- 5. Create Oversight and Transparency Boards:
 - Require that any public health database be overseen by an independent board that includes disability rights advocates, ethicists, and cybersecurity experts.
- 6. Empower Citizens to Opt Out and Sue:
 - Allow individuals to opt out of any such database and provide them with the legal right to sue if their data is collected without consent.

We can look to Illinois as an example of a state fighting back for its constituents. Recently, the Governor of Illinois, wrote an executive order that says state agencies cannot collect or disclose personally identifiable autism-related data unless it is required for care, legal compliance, or program eligibility (7). It says when that information is shared, it must follow strict privacy and data guidelines (7). I personally believe that alone is not enough. We must protect individuals' private health information - regardless of if it is about Autism, Abortion, or anything else - because we live in a time where these assaults upon our privacy rights are becoming commonplace.

In conclusion, I would like to stress that any weakening of our rights to private health information will not just stop at those that are targeted in HB 96. It will not simply stop at abortion. And our increased foray into mass surveillance will not simply stop at the collection of private medical information of stigmatized conditions. An attack on any of our rights is an attack on all of our rights.

I respectfully ask you to remove these changes from the Senate version of HB 96 and instead support legislation that respects patient confidentiality and affirms the right to private and safe access to healthcare in all of its forms.

Thank you for your time and service to the people of Ohio.

Sincerely,

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Sources:

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