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## Healthcare Privacy and Disability Rights

The Delaware Developmental Disabilities Council (DDC) believes that every person, including people with disabilities, has the right to privacy when it comes to their personal healthcare information.

In accordance with The Health Insurance Portability and Accountability Act (HIPAA)<sup>1</sup> and [Family Educational Rights and Privacy Act](#) (FERPA)<sup>2</sup> the DDC strongly opposes the creation of any database, platform, or registry that collects, stores, or shares healthcare information about individuals with disabilities without their full understanding, agreement, and permission.

Healthcare information is personal and sensitive. Collecting or using this information without clear consent can cause serious harm, including:

- Violating Privacy: Healthcare information belongs to the individual. It should not be collected, shared, or used without permission.
- Increasing Discrimination: Using private health information improperly can lead to discrimination in healthcare, education, employment, housing, and other areas of life.
- Creating Fear and Distrust: People with disabilities may avoid needed services if they are worried about how their private information could be used against them.
- Risking Safety and Independence: Misuse of private health data could put individuals' safety, independence, and opportunities at risk.

The DDC believes:

- People with disabilities must have the same strong protections for their private health information as everyone else.
- Healthcare decisions and information must remain between the individual and their trusted providers, unless the person freely chooses to share it.
- Programs, research, and services must always be built with respect for individual privacy, dignity, and choice.

The DDC stands firmly against any action that could weaken privacy protections for people with disabilities.

We are committed to defending the rights, safety, and dignity of all individuals with disabilities.

1. U.S. Code of Federal Regulations (CFR) at 45 CFR Part 160 and Subparts A and E of Part



The Delaware Developmental Disabilities Council is federally funded in compliance with the DD Act.

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2. 20 U.S.C. § 1232g and FERPA regulations 34 CFR Part 99

**Adopted June 11, 2025**