

Right to Privacy – Confidentiality of Information Position Statement

The Texas Council for Developmental Disabilities recognizes that people with disabilities have the same right to privacy as any other. Privacy refers to both the protection of one's personal life from intrusions by others and protection of information about oneself. The Fourth Amendment of the U.S. Constitution provides "the right of people to be secure in their persons, houses, papers, and effects, against unreasonable searches and seizures." With respect to protection of personal information, confidentiality has historically been a cornerstone in providing medical care and related human services to people.

In an age of rapidly evolving communication technologies, the Council recognizes the positive role electronic media plays in the compilation and exchange of information. Government agencies, businesses, and non-profits can quickly exchange information and gather and analyze massive amounts of data. This helps in streamlining business, reducing costs, and ensuring appropriate services for people. However, this increased capacity for data collection can also be used intentionally or unintentionally to the detriment of the people served by government agencies. The Council supports the following basic principles for all information and data collection systems:

- Individuals, government entities, nonprofit organizations, and businesses have a shared responsibility for the secure use and protection of personal identifying information.
- Prior to the collection and disclosure of personal identifying information, each individual must consent and receive a copy of the consent to disclosure of the:
 - specifics of personal identifying information to be collected and/or disclosed;
 - dates of the time-limited period during which the consent is valid;
 - name, address, and phone number of both the entity which is collecting the information and the entity to which the information will be disclosed;
 - purpose for which the information is to be collected and/or disclosed;
 - individual's legal rights to privacy and confidentiality of personal identifying information;
 - administrative procedures to follow to review personal information;
 - process to remove, correct or add information that has been entered in a data collection system;
 - way to file a complaint and claim damages in the case of improper use and/or disclosure of personal information; and
 - degree and nature of any risk that personal identifying information may be collected by other entities through the electronic transmission processes.

- Those who obtain, possess or retain personal identifying information of others must ensure it is not shared with, obtained by, or collected by unauthorized parties through the process of electronic data transmission.
- Personal identifying information should only be disclosed with the consent of the individual. Personal identifying information includes:
 - name, home address, phone number, or email address;
 - photograph, audio and/or video recording, fingerprints, or biologically specific markers, including DNA;
 - social security number, driver's license number, passport number, or other government-issued identification;
 - date of birth
 - religious, political or organizational affiliations;
 - employment, educational, medical, psychiatric, psychological, and financial status or details;
 - legal status or history; and
 - gender and marital status.

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