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# Fact Sheet on Privacy Protection

The California Department of Developmental Services (the Department) and the 21 regional centers support over 500,000 individuals with intellectual and developmental disabilities (Individuals). Support is delivered through services and resources that are designed for individuals and their families, representatives, and advocates.

As part of designing and providing these services, the Department and the regional centers collect, maintain, and use only the personal information that is necessary to accomplish this mission. Federal and state privacy laws say that the Department and the regional centers may not disclose information about you without your permission, unless there is another law that allows them to do so.

**IMPORTANT:** This Fact Sheet provides an overview of your legal rights to privacy. The law describes some situations in which your information may be disclosed. Please see the [Notice of Privacy Practices](#) for a complete list of how your information may be used and disclosed, and how you can access your information.



### How do DDS and the Regional Centers use my Personal Information?

DDS and the regional centers must give you a Notice of Privacy Practices.<sup>i</sup> This Notice tells you how your personal information will be used and disclosed. It tells you who might see your information, what your rights are, and where to complain. DDS' Notice of Privacy Practices can be found here: [Notice of Privacy Practices](#).



### Who is able to access my Personal Information?

DDS and the regional centers have to ask for your written permission before

they can release your personal information to others, unless there is a law which permits the release, such as for purposes of treatment, payment, or health care operations, or when the law requires release of the information.<sup>ii</sup>

Your written permission to release information sometimes is called an "authorization." It must state what information can be released, to whom, and for what purpose. You have the right to say "no" without fearing pressure or retaliation. You have the right to change your mind at any time and take back your written authorization.<sup>iii</sup>



### **May I see information about myself in my records?**

You may ask to read or make copies of your information in your records with DDS and the regional centers. You can make the request for your DDS records at the following link: [Records Request](#). You will need to contact your regional center directly if you wish to access or make copies of your regional center records.

If your request is denied, you must be told why. There is a process for you to seek another review if your request is denied.<sup>iv</sup>



### **How do I make corrections to the information in my records?**

You may ask DDS and the regional centers to change information about you in your records if you believe it is not correct or complete. DDS and the regional centers may deny your request. If this happens, you may add a statement to your file explaining the information.<sup>v</sup> You can find the form to request changes to your DDS records here: [Request to Amend Personal Information](#). You will need to contact your regional center directly if you want to make a change to your regional center information.



### **Have DDS or the regional centers provided my personal information to other people?**

You have a right to ask DDS and your regional center who has received your personal information.<sup>vi</sup> This is called an “accounting of disclosures.” It must include the date of the disclosure, the name of the person who received the

information, what information was disclosed, and the purpose of the disclosure.<sup>vii</sup> There are some exceptions to this requirement, such as disclosures requested by you or for purposes of treatment, payment, or health care operations.<sup>viii</sup> If you would like an accounting of disclosures from DDS, please email [privacyofficer@dds.ca.gov](mailto:privacyofficer@dds.ca.gov).



### **What do I do if I believe that DDS or a regional center has violated the law?**

If you have concerns that DDS or one of the regional centers has violated the law in handling your information, DDS has multiple options for you to file a complaint, which can be found here: [Appeals & Complaints](#).

If you are a resident at Porterville Developmental Center or Canyon Springs Community Facility, and feel that the facility violated the law regarding the privacy or confidentiality of your personal information, you may file a complaint with the California Department of Public Health at [HIPAA/Privacy Complaint form](#).

You also have the right to complain to the federal Office of Civil Rights about possible violations of federal health law regarding the privacy or confidentiality of your personal information: [U.S Office for Civil Rights Complaint Portal Assistant](#).

California law gives you the right to bring a lawsuit to recover damages in some cases of violation of state laws and health information privacy.<sup>ix</sup>



**Does this Fact Sheet apply to me even if I am not a U.S. citizen?**

Yes, these rights apply to all individuals supported by regional centers, and their families, regardless of their immigration status. Under a rule issued by the Homeland Security on September 8, 2022, non-citizens who receive health or other benefits to which they are entitled will not suffer harmful immigration consequences as a result of receiving that healthcare or benefit.<sup>x</sup>



**Will my immigration information be shared with the federal government?**

DDS and the regional centers will not voluntarily disclose your immigration information to Federal agencies. However, we may be compelled to do so if required by law or a court order.



**Will my reproductive healthcare information be disclosed for investigations?**

DDS and the regional centers will not use or disclose your information for criminal, civil, or administrative investigations for the mere act of seeking, obtaining, providing, or facilitating reproductive healthcare where such health care is lawful under the circumstances in which it is provided unless compelled to do so when required by law or a court order.<sup>xi</sup>



**Are there additional resources that might help me understand my privacy rights over my Personal Information?**

- DDS Privacy Policy Page: <https://www.dds.ca.gov/general/privacy-policy/>
- DDS Notice of Privacy Practices: [DS-5310 Consumer Notice of Privacy Practices 20230905.docx](#)
- DDS Request for Access and/or Copies of your personal information form: [Request for Access and/or Copies of Personal Information \(DS 5410\)](#) or at the following link: [Records Request](#)
- DDS Request to Amend your personal information form: [Request to Amend Personal Information \(DS 5210\)](#)
- California Department of Justice: [Consumer Privacy Resources](#)

**This fact sheet is for informational purposes and should not be construed as legal advice or as policy of the State of California. It is based on the cited laws, as they exist in December 2024.**

**If you want advice on a particular issue, you should consult an attorney or other expert. Here are lists of publicly funded legal services and immigration attorneys.**

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<sup>i</sup> On Notice of Privacy Practices: 45 C.F.R. § 164.520; DDS' Notice of Privacy Practices can be found here: [DS-5310 Consumer Notice of Privacy Practices 20230905.docx](#).

<sup>ii</sup> On Authorizations and Uses and Disclosures Without Authorizations: 45 CFR §§ 164.506, 164.508, and 164.512; [California Welfare & Institutions Code, § 4514](#).

<sup>iii</sup> Elements of Valid Authorization: 45 CFR § 164.508; California Welfare & Institutions Code, § 4514.

<sup>iv</sup> Right to Access: 45 CFR § 164.524; California Civil Code §§ 1798.32, 1798.34; California Health & Safety Code § 123140

<sup>v</sup> Right to Amend: 45 CFR § 164.526; California Civil Code § 1798.35

<sup>vi</sup> Right to Accounting of Disclosures: 45 CFR § 164.528(a); California Civil Code §§ 1798.25 and 1798.28

<sup>vii</sup> Elements of Accounting of Disclosures: 45 CFR § 164.528(b); California Civil Code §§ 1798.25 and 1798.28

<sup>viii</sup> Exceptions to Accounting of Disclosures: 45 CFR § 164.528(a); California Civil Code §§ 1798.25 and 1798.28

<sup>ix</sup> Remedies: California Civil Code §§ 1798.45-1798.57; California Welfare & Institutions Code § 4518

<sup>x</sup> [New Rule Makes Clear that Noncitizens Who Receive Health or Other Benefits to which they are Entitled Will Not Suffer Harmful Immigration Consequences | HHS.gov](#)

<sup>xi</sup> [Federal Register 2024-08503 - HIPAA Privacy Rule to Support Reproductive Health Care Privacy](#)