**Possible Updates to Data Categories**

People should be able to see themselves and their communities in the data about California’s developmental disabilities services system. This data should be consistently collected and categorized. To further improve the quality and consistency of California’s data, the California Department of Developmental Services (Department) is seeking your input on possible updates to data collection in the following categories:

1. Race and ethnicity
2. Preferred language
3. Where people live (also known as “residence codes”)
4. Sexual orientation and gender identity
5. Legal status (the data used to identify conservatees, foster youth, and other populations)

These possible updates were developed considering California and federal laws and regulations, federal standards used by the Census Bureau and the Centers for Medicare and Medicaid Services (CMS), California’s Department of Finance demographic information, recent state and federal audits of other state agencies, the California Health and Human Services (CalHHS) Data Exchange Framework for health care information, the language access efforts of both the California Health and Human Services Agency and the Government Operations Agency, and input heard during various community forums unrelated to data definitions. These documents solely are for the purpose of obtaining input, and are not proposals from the Department.

**Each document can be downloaded to your own computer. We welcome your comments, suggestions, and concerns, on any or all of the categories.** Please submit your input by email to dtf@dds.ca.gov, which is the email account used by the Department’s data task force. We also plan to have some future webinars and virtual listening sessions to collect input. Input received by the end of April 2024 will be considered.

Once the data to be collected in these categories has been updated, DDS will work with local partners to revise data systems, train regional center employees, and provide educational materials to community members. It is expected that the quality and consistency of California’s data will improve over time following these changes. Individuals will continue to have the right to see information collected about them, and their privacy rights will not change.

You can provide comments on any, or all, of these categories. Thank you in advance for your contributions to improving California’s data so that it better reflects individuals, families, and communities.

Here are some ideas to consider as you provide input on potential changes:

1. This document contains possible changes. You can suggest other possible changes.
2. The possible changes in this document are about “what” information is collected, not “how” it would be collected.
3. People should be able to choose how they are identified.
4. People should have more than one available option to describe themselves.
5. Detailed information can be combined into larger categories to continue to protect the privacy of individuals and make reporting easier.
6. Too many categories can make it difficult to understand or respond to.