

## The Department of Developmental Services

### Self-Advocate and Family Survey

The Department of Developmental Services' (DDS) highest priority is the safety of Californians with intellectual and developmental disabilities. As a result of COVID-19, self-advocates and families have faced changes in almost every part of their lives. DDS is working with self-advocates, family members, service providers, and regional centers to continue finding new and effective ways to support consumers and families during these challenging times.

DDS wants your feedback about your experiences working with your regional center and service providers to get the services, supports, and resources you need for you and your family. Please take a few minutes to complete this survey and share your experience. DDS will post the aggregate data on its website and the information will be used to guide DDS' work. Individual survey responses will not be shared.

1. Which of the following best describes you?
  - Self-Advocate/I Receive Services from a Regional Center
  - Family Member
  - Legal Guardian/Conservator
  - Other
  
2. What regional center provides you or your family member services?  
**[ADD drop down menu of RC or link to RC Map]**
  - Alta California Regional Center
  - Central Valley Regional Center
  - Eastern Los Angeles Regional Center
  - Far Northern Regional Center
  - Golden Gate Regional Center
  - Harbor Regional Center
  - Inland Regional Center
  - Kern Regional Center
  - Lanterman Regional Center
  - North Bay Regional Center
  - North Los Angeles County Regional Center
  - Redwood Coast Regional Center
  - Regional Center of East Bay

- Regional Center of Orange County
- San Andreas Regional Center
- San Diego Regional Center
- San Gabriel Pomona Regional Center
- South Central Los Angeles Regional Center
- Tri-Counties Regional
- Valley Mountain Regional Center
- Westside Regional Center

3. What is your ethnicity? Check all that apply.

- Asian Indian
- Black/African American
- Chinese
- Filipino
- LatinX/Hispanic
- Native American
- Pacific Islander
- Vietnamese
- White
- Other
- Prefer not to state

4. For the person receiving regional center services, what is their age group? If you have more than one person receiving regional center services in your family, you may select multiple age groups. [ADD box for more than one family member]

- 0-2
- 3-22
- 23-49
- 50-65
- 65+

5. What has been helpful for you and your family during COVID-19?

[ADD the following options for each bubble: Not helpful, somewhat helpful, helpful, very helpful, don't know, not applicable option]

- Programs offered by Community-Based Organizations (e.g., Family Resource Center, Promotora, Integradora)
- Support from family
- Support from friends

- Communication and support from my regional center, including from my service coordinator
- Working with my service providers. If so, in what way: **[ADD drop down menu]**
  - by phone
  - video
  - in-person
- Utilizing technology to access my existing services and resources, such as through video meetings rather than in-person
- Receiving Personal Protective Equipment (PPE) (e.g., masks, face shields, and hand sanitizer)
- Services from other systems outside of the regional center system  
If so, from what other system? **[ADD drop down menu]**
  - Schools
  - In-Home Support Services
  - CalFresh
  - Local foodbank
  - Mental Health
  - Applied Behavior Analysis (ABA Therapy)
- Other **(ADD TEXT BOX)**

6. Did you or your family need additional regional center services or support during the COVID-19 pandemic?

- Yes
- No

7. If yes to question 6, how has your regional center supported you during the COVID-19 pandemic? **[ADD the following options for each bubble: Not helpful, somewhat helpful, helpful, very helpful, not needed, don't know, not applicable option]**

- My service coordinator contacted me
- Helping me find important information and resources
- Assistance with finding me new services and supports
- Offering new or additional services and supports
- Offering flexible service options (e.g., Participant Directed Services, such as respite or day care), day program staff helping with food and other critical supply delivery, etc.),
- Technology resources (e.g., equipment, telehealth)
- Providing Personal Protective Equipment (e.g. masks, face shields, and hand sanitizer)

- Connecting me to concrete resources such as food, financial support, diapers, or other needs
- Providing health resources and information about COVID-19
- Website was helpful
- Other (ADD TEXT BOX)

8. If yes to question 7, have you contacted your regional center service coordinator to seek the assistance you need?

- Yes
- No

9. How often has your Service Coordinator contacted you since the COVID-19 pandemic started mid-March?

- More than 6 times (more often than once per month)
- 5-6 times (about monthly)
- 3-4 times (about every other month)
- 1-2 times
- Never

10. In response to your changing needs related to the COVID-19 pandemic, would you like your Regional Center Service Coordinator to contact you

- More than they do now
- Less than they do now
- Stay the same

11. If you feel you have not received the support you have needed from your regional center during the COVID-19 pandemic, choose all the answers that explain why:

- Not enough service coordinator communication or contact
- Did not offer additional services to meet emergency needs
- Did not explain new service options
- Did not help me access services from other agencies
- Other (ADD TEXT BOX)

12. If you are currently receiving services from at least one regional center funded service provider, how have these services been provided to you during the COVID-19? Choose all answers that apply.

- Remote service delivery (e.g., phone, video, Zoom)

- Community-based services in a safe manner (such as masks, physical distancing)
- Home based services in a safe manner (such as masks, physical distancing)
- My service provider has not provided services or the kind of support I need during COVID-19. I have not received services because:
  - My service provider did not contact me
  - No services were offered
  - The services offered were not helpful
  - The amount of service was not enough
  - The service was considered non-essential and could not be provided
  - I declined the service
- I declined at least one service
- I do not have a service provider
- Other (ADD TEXT BOX)

13. If you feel you have not received the support you need from at least one regional center funded service provider, choose all of the answers that explain why:

- Not enough service provider communication or contact
- Not enough staffing available
- No alternative options to in-person service delivery offered
- Only remote services offered (such as phone, video, or Zoom)
- I don't feel safe having someone come to my home
- I don't feel safe going to a site-based service
- Not following safety measures
- I declined services for some other reason.
- Does not apply - not getting services currently
- Other (ADD TEXT BOX)

14. Please let us know if you have access to the internet.

- Yes, I have access to the internet
- No, I do not have access to the internet
- I need help accessing the internet
- Other (ADD TEXT BOX)

15. If you have access to the internet, how important has the internet been for you and your family during COVID-19?

- Very important
- Important
- Not Important
- I need help using the internet
- I do not have access to the internet
- Do not know

16. If you would you like to learn more about how to keep you and your family safe and reducing the community spread of COVID, choose your top 3 areas:

- Wearing a face mask properly and using other personal protective equipment (PPE)
- Learning about emergency preparedness and safety for your home and family
- Accessing health care resources for COVID-related symptoms and non-COVID health care needs
- Accessing regular health care services and check-ups safely during COVID
- Understanding the State's rules and guidelines about COVID
- Understanding various service provider rules and guidelines about COVID
- I do not need to learn more about COVID
- Other (ADD TEXT BOX)

17. If you would like to learn more about regional center services and supports, choose your top 3 areas to learn about:

- My rights in choosing how and when services are provided in my home and by whom
- Alternative options to receive supports (e.g., Participant Directed Services or PDS)
- Remote options to receive supports (e.g., phone, video day services, tele-medicine)
- Guidance DDS has provided to regional centers, service providers, families and self-advocates
- How the DD system is helping families plan what services they need during COVID?
- I do not need to learn more about regional center services
- Other

18. How do you prefer to receive communication from your regional center?  
Check all that apply.

- Email
- Text message
- Phone call
- Video check-in
- Other (ADD TEXT BOX)

19. What is the best way for you and your family to receive updates from DDS? Check all that apply.

- Updates from my regional center service coordinator
- Community information provided by my regional center (e.g., regional center website, Zoom Meetings, etc.)
- Social media (Facebook, website, etc.)
- Provide written information or updates by U.S. Mail
- Statewide Zoom Meeting or Webinar
- Statewide Call or Text (e.g., Everbridge)
- Contact my organization (e.g., Community Based Organizations or Family Resource Centers)
- Email
- Other (ADD TEXT BOX)

Participant Directed Services (PDS) provides individuals the option to exercise more control and flexibility on how, and by whom services are provided, including hiring of staff. PDS can be used for services such as respite, and day care. In response to COVID, DDS expanded PDS to include independent living skills, personal assistance and supported employment.

20. Are you currently receiving PDS? (APPLY SURVEY LOGIC) If yes, please answer questions 15-19:

21. How did you first learn about Participant Directed Services (PDS)?

- Information from my regional center
- A community-based organization
- Written information shared with me
- Family member or friend
- Internet

22. Has using PDS been helpful to you and your family during COVID?  
*[ADD the following options for each bubble: Not helpful, somewhat helpful, helpful, very helpful, don't know]*

23. If PDS has been helpful, check all that apply:

- I choose my own staff who meet my needs in a safe way
- I can schedule the hours my staff can work to meet my/family's needs
- I can find staff who speak my family's language
- PDS provides the opportunity for me to use innovative resources (e.g., phone or video technology, telehealth)
- Other **(ADD TEXT BOX)**

24. If you feel that PDS has not been helpful to you, check all that apply:

- I received information about these services, but it was too hard to understand
- I could not find a Financial Management System provider to be the employer of record
- It was too hard to find staff who could provide the services
- Other **(ADD TEXT BOX)**

Individuals who were selected as part of the Self-Determination Program (SDP) during the "phase in period" will be emailed a survey about their experience. SDP will be available state-wide in June 2021. If you are interested in the self-determination program, you may contact your regional center service coordinator. To learn more about self-determination, go to the DDS webpage [here](#).

***Thank you for completing this survey.***