

Survey: Barriers to Regional Center Eligibility & Services

The Stanford Intellectual & Developmental Disabilities Law & Policy Project (SIDDLAPP), Disability Rights California (DRC), Disability Voices United (DVU), and the Integrated Community Collaborative (ICC) are gathering information about difficulties people have experienced in obtaining services from their local Regional Centers SINCE 2018.

This survey is confidential, so there is no way for anyone (including Stanford Intellectual & Developmental Disabilities Law & Policy Project, Disability Rights California, Disability Voices United, and the Integrated Community Collaborative) to determine your identity, unless you provide your name and contact information at the end of this survey so we may contact you for more information.

If you would like to participate, please begin by selecting your regional center from the menu below.

Regional Center [DROP-DOWN MENU]:

- Alta
- Central Valley
- East Bay
- Eastern Los Angeles
- Far Northern
- Frank D. Lanterman
- Golden Gate
- Harbor
- Inland
- Kern
- North Bay
- North Los Angeles County
- Orange County
- Redwood Coast
- San Andreas
- San Diego
- San Gabriel/Pomona
- South Central Los Angeles
- Tri Counties
- Valley Mountain
- Westside

Are you a:

- Regional Center consumer
- Parent/family member/guardian of a Regional Center consumer

Race [CHECKLIST; select all that apply]:

- White
- Black/African-American
- Asian
- American Indian or Alaska Native
- Native Hawaiian or Other Pacific Islander

Ethnicity [MULTIPLE CHOICE; select one]:

- Hispanic or Latino
- Not Hispanic or Latino

Primary language [MULTIPLE CHOICE; select one]:

- English
- Spanish
- Chinese
- Tagalog
- Vietnamese
- Korean
- Other:

Instructions

Please check the box next to any of the following statements that describe your personal experience(s) SINCE 2018.

BECOMING ELIGIBLE FOR REGIONAL CENTER SERVICES (since 2018)

Check all that apply SINCE 2018:

1. I did not know/understand which types of disabilities were eligible for services through the Regional Center system.
2. I did not know/understand how severe the disability had to be to qualify my child (or me) for services through the Regional Center system.
3. I could not afford to pay a specialist to complete a written assessment about my child's (or my own) disability before I applied for Regional Center services.
4. The Regional Center told me that they could not schedule an intake to assess my child's (or my own) eligibility for services unless I could provide a written assessment from a specialist about my/my child's disability.
5. After the Regional Center denied my child's (or my own) eligibility for services, I did not agree with them, but could not afford to pay a specialist to complete a written assessment about my child's (or my own) disability.

More Comments about Becoming Eligible for Regional Center Services:

SCHEDULING AND PREPARING FOR THE IPP (since 2018)

Check all that apply SINCE 2018:

6. When I asked for a meeting with the Regional Center to talk about my child's (or my own) need for services, either through an IPP meeting or some other type of meeting, the Regional Center delayed scheduling it.
7. When I asked for a meeting with the Regional Center to talk about my child's (or my own) need for services, the Regional Center agreed to schedule a meeting but would not call it an IPP meeting.
8. When I asked for a meeting with the Regional Center to talk about my child's (or my own) need for services, I did not know what information or paperwork I should bring to the meeting to show what services were necessary and why.
9. When preparing for an IPP meeting that was going to be held in person, I wanted someone else (such as a friend, caregiver, relative, navigator, doctor or integradora) to come with me to the meeting, but they couldn't come because it was too hard or time-consuming for them to travel to and from the meeting.
10. When I was preparing for an IPP meeting that was going to be held in person, the Regional Center DID NOT tell me that anyone I wanted to help me during the meeting (such as a friend, caregiver, relative, navigator, doctor or integradora) could participate in person, by phone, or by video conference (such as Zoom).
11. When I was preparing for an IPP meeting that was going to be held in person, I wanted someone I thought could help me (such as a friend, caregiver, relative, navigator, doctor or integradora) participate by phone or video conference (such as Zoom), but the Regional Center DID NOT allow it.
12. When I was preparing for an IPP meeting that was going to be held by video conference (such as on Zoom), the Regional Center DID NOT tell me that anyone I wanted to help me during the IPP meeting (such as a friend, caregiver, relative, navigator, doctor or integradora) could participate.
13. When I was preparing for an IPP meeting that was going to be held by video conference (such as on Zoom), I asked for someone I thought could help me (such as a friend, caregiver, relative, navigator, doctor or integradora) to participate, but the Regional Center DID NOT allow it.

More Comments about Scheduling and Preparing for the IPP:

AT THE IPP MEETING (since 2018)

Check all that apply SINCE 2018:

14. When I asked for services at the IPP meeting, the Regional Center staff who came to the meeting told me it wasn't up to them to decide, and they had to check with someone else at the Regional Center to see if I could get those services.
15. When I asked for a service during the IPP meeting that I thought was necessary for my child (or for myself), the Regional Center said no but did not tell me why in a way I could understand.

16. During the IPP meeting, I felt like the Regional Center didn't take what I said seriously.
17. When the Regional Center said during the IPP meeting that they could not provide a service I thought was necessary for my child (or myself), I had more questions or wanted to discuss further, but the Regional Center ended the conversation and said they would send me a Notice of Action.
18. At the end of the IPP meeting, I did not understand exactly what the Regional Center had agreed to do.

More Comments about the IPP Meeting

AFTER THE IPP MEETING

Check all that apply SINCE 2018:

19. After my IPP meeting, the Regional Center staff had another meeting I was not invited to where they decided not to give me the services I had asked for.
20. Even though the Regional Center agreed to give me a service and a provider was willing to start providing that service immediately, my child (or I) didn't start getting the service for over a month because it took the Regional Center so long to finish the paperwork.
21. After my IPP meeting, it took the Regional Center months to give me an answer on whether they would provide a service I had asked for, even though I gave them all the information they asked for right away.
22. The Regional Center sent me a Notice of Action after my IPP meeting, but I didn't read it because I didn't know what it was.
23. The Notice of Action I received after my IPP meeting said that the Regional Center would not give me a service I wanted, but didn't explain why in a way I could understand.
24. When I received a Notice of Action, I requested a fair hearing because it seemed like the only way to get the services I wanted, even though I wasn't sure what that was or what I would have to do.
25. When I received a Notice of Action, I didn't request a fair hearing because it seemed too hard to try to go up against the Regional Center in front of a judge.
26. The Regional Center sent me a Notice of Action after my IPP meeting, but after reading it, I still did not understand what an "informal meeting" was or how it could help me get the services I requested.
27. When the Regional Center sent me a Notice of Action, I checked the box for an "informal meeting" even though I did not understand what that was..
28. The Regional Center sent me a Notice of Action after my IPP meeting, but after reading it, I still did not understand what a "mediation" was or how it could help me get the services I requested.
29. When the Regional Center sent me a Notice of Action, I checked the box for an "mediation" even though I did not understand what that was.

More Comments about After the IPP Meeting

BEFORE AND AT AN INFORMAL MEETING

Check all that apply SINCE 2018:

30. Although I requested an “informal meeting” with my Regional Center, I didn’t understand beforehand who would be in charge of the meeting, what my rights were, or what I should do to prepare, such who I should bring with me, what I should say or not say, what documents I should bring, etc.
31. When I tried to prepare for an informal meeting with my Regional Center by asking the Regional Center for my file, the documents they gave me did not include “Interdisciplinary Team Notes” (“IDT Notes”).
32. Although I asked my Regional Center for the Interdisciplinary Team Notes (IDT Notes) to help prepare for an informal meeting the Regional Center, did not provide them to me.
33. I could not afford to pay for a lawyer to help me at my informal meeting.
34. Someone I wanted to support me at my informal meeting (such as a friend, caregiver, relative, navigator, doctor or integradora) was not allowed to attend.
35. Because my informal meeting was held in person, someone I wanted to come and help me (such as a friend, caregiver, relative, navigator, doctor or integradora) could not come, because it was too hard for them to travel back and forth.
36. Because my informal meeting was held by video conference (such as on Zoom), someone I wanted to be there with me (such as a friend, caregiver, relative, navigator, doctor or integradora) was able to attend.

More Comments about Before & At an Informal Meeting

BEFORE AND AT THE MEDIATION (since 2018)

Check all that apply SINCE 2018:

37. Although I requested a “mediation” with my Regional Center, I didn’t understand beforehand who would be in charge of the mediation, what my rights were, or what I should do to prepare, such who I could bring with me, what I should say or not say, what documents I should bring, etc.
38. When I tried to prepare for a mediation with my Regional Center by asking the Regional Center for my file, the documents they gave me did not include “Interdisciplinary Team Notes” (“IDT Notes”).
39. Although I asked my Regional Center for the Interdisciplinary Team Notes (IDT Notes) to help prepare for a mediation, the Regional Center did not provide them to me.
40. I could not afford to pay for a lawyer to help me at my mediation.
41. Someone I wanted to support or help me at my mediation (such as a friend, caregiver, relative, navigator, doctor or integradora) was not allowed to attend.

42. Because my mediation was held in person, someone I wanted to come and help me (such as a friend, caregiver, relative, navigator, doctor or integradora) could not come, because it was too hard for them to travel back and forth.
43. Because my mediation was held by video conference (such as on Zoom), someone I wanted to be there with me (such as a friend, caregiver, relative, navigator, doctor or integradora) was able to attend.

More Comments about Before & At the Mediation

BEFORE AND AT THE FAIR HEARING (since 2018)

Check all that apply SINCE 2018:

44. Although I requested a “fair hearing” with my Regional Center, I didn’t understand beforehand how it would work or what I should do to prepare, such as who I could bring with me, what I should say or not say, what documents I should bring, etc.
45. When I tried to prepare for a fair hearing with my Regional Center by asking the Regional Center for my file, the documents they gave me did not include “Interdisciplinary Team Notes” (“IDT Notes”).
46. Although I asked my Regional Center for the Interdisciplinary Team Notes (IDT Notes) to help prepare for a fair hearing, the Regional Center did not provide them to me.
47. I could not afford to pay for a lawyer to help me at my fair hearing.
48. Someone I wanted to support or help me at my fair hearing (such as a friend, caregiver, relative, navigator, doctor or integradora) was not allowed to attend.
49. Someone I wanted to support me at my fair hearing (such as a friend, caregiver, relative, navigator, doctor or integradora) was allowed to be a witness, but was not allowed to help me in any other way.
50. Because my fair hearing was held in person, someone I wanted to testify as a witness could not come, because it was too hard for them to travel back and forth.
51. Because my fair hearing was held in person, someone I wanted to be there with me (such as a friend, caregiver, relative, navigator, doctor or integradora) could not come, because it was too hard for them to travel back and forth.
52. Because my fair hearing was held by video conference (such as on Zoom), someone I wanted to be a witness for me (such as a friend, caregiver, relative, navigator, doctor or integradora) was able to attend.
53. Because my fair hearing was held by video conference (such as on Zoom), someone I wanted to be there with me (such as a friend, caregiver, relative, navigator, doctor or integradora) was able to attend.
54. At the fair hearing, I felt like the judge was on the Regional Center’s side even before I could tell my side.

More Comments about Before & At the Fair Hearing

After the Fair Hearing (since 2018)

Check all that apply SINCE 2018:

- 55. After I won the fair hearing, it didn't seem fair that the Regional Center didn't have to give us anything, such as extra services, to make up for the months (or years) before the hearing when we didn't get the services we had a right to.
- 56. I did not agree with the fair hearing judge's decision, but I could not afford to pay for a lawyer to appeal the judge's decision.
- 57. After the fair hearing judge decided my child (or I) was not eligible for Regional Center services, the Regional Center would not schedule another intake, even though I had new information after the fair hearing that showed more clearly why my child (or I) was eligible.
- 58. After the fair hearing judge decided my child (or I) I was not entitled to a particular service I had requested, the Regional Center automatically rejected all of my requests for that service, even though my circumstances changed after the hearing so I needed it even more than before.

More Comments about After the Fair Hearing:

Any Additional Comments:

If you would like to share any more details about your experiences without sharing your name or contact information, please do so here.

OPTIONAL: Contact Information

If you would be willing to talk with us to provide more detail about your experiences, please write your contact information below.

Your responses and contact information will not be shared with anyone besides those conducting this survey (Stanford Intellectual & Developmental Disabilities Law & Policy Project, Disability Rights California, Disability Voices United, and the Integrated Community Collaborative) without your permission.

Name: _____

Cell Phone Number: _____

E-mail: _____

If you do not want to share your information to talk with us about your experiences, you can leave all of the lines in this section blank and just click the Submit button below.