

# California's Self-Determination Program (SDP):

## *What Participants Think*

Prepared By:



**UCLA** Tarjan Center



This is a plain language report. It looks at how well California is meeting the goals of the Self-Determination Program. It also suggests changes that could make the programs better.

The following organizations contributed to this report.

- State Council on Developmental Disabilities (SCDD)
- University of California Los Angeles (UCLA)
- Disability Rights California (DRC)
- University of California Davis (UCD)
- University Centers for Excellence in Developmental Disabilities, University of Southern California (USC)

## Why We Made This Report

A 2013 California law ordered Department of Developmental Services (DDS) to make a Self-Determination Program (SDP). The goal of the law was to give people with developmental disabilities more control over their lives. By April 2023, almost 2700 people in regional centers were in the SDP.

Today, all regional centers have a SDP option. The SDP is a good match for regional center clients and their families that want **more**:

- Choices
- Flexibility
- Control
- Resources
- Services and Supports

With the SDP, clients and families have more say in their Individual Program Plan (IPP). This includes more freedom, power, and support to participate in and approve their own IPP. California's SDP law requires us to:

- Report on the SDP participants' experience.
- Describe how well the SDP is meeting its original goals.
- Recommend changes that would make the SDP better.

The organizations that made this report are listed on the cover page.

We used strong research methods to connect with the SDP participants and regional center clients to make this report. We asked about their:

- Opinions
- Experiences
- Ideas to Make the Program Better

We also got input from families and people that worked closely with the program.

In this report, we use the term "participants" to mean program participants, their families, and other stakeholders.

This report has 5 parts. You can read them all, or just click on the ones that interest you.

- [1. What We Learned from SDP Participants](#)
- [2. How We Connected with SDP Participants](#)
- [3. What SDP Participants Told Us](#)
- [4. How to Improve SDP](#)
- [5. Future Research](#)

### What We Learned from SDP Participants

Participants reported good things about the SDP and some things that need to get better.

Good Things	Some Things Need to Get Better
SDP participants say:	SDP participants say:
<ul style="list-style-type: none"><li>• They like the program, especially the program’s values, and would recommend the SDP to others.</li></ul>	<ul style="list-style-type: none"><li>• Some changes are needed.</li></ul>
<ul style="list-style-type: none"><li>• They agree that people with developmental disabilities should have more control over their own lives.</li></ul>	<ul style="list-style-type: none"><li>• The program is hard to sign up for, understand, and stay connected with.</li></ul>

### How We Connected with SDP Participants

We collected information from **604 people in different stages of SDP**, including:

- 244 program participants.
- 314 parents and caregivers.
- 20 Independent Facilitators (IF).
- 14 others, like other relatives and legal guardians.
- 12 people that did not tell us who they represented.

We spent 7 months and used 3 different ways to connect with participants:

Method	Number of People	Comment
Online multiple-choice survey.	242 people	
Virtual focus groups.	97 people	
Online survey with open-ended questions.	265 people	None of these people were in our Zoom focus groups.

## What SDP Participants Told Us

### 1. SDP participants support SDP goals.

One of the most common things we heard in the focus groups and read in the surveys was that users agreed with the SDP goals to:

- Give people with developmental disabilities and their families more freedom and control over their lives.
- Let each person choose the services and supports they prefer.

They also said the program gives them hope, and they want the SDP to succeed.

### 2. The SDP moves participants closer to self-determination.

Our participants told us that the SDP helped them be self-determined. Many participants told us they really liked having the freedom and power to make important choices in their lives, like choosing providers and deciding the kinds of services they needed. People in the SDP also said they had better access to services and were able to pay their providers more. This suggests that people in the SDP see a lot of positives about it.

About 70% of SDP participants (in our multiple-choice survey) said they were happy with their living situation and their freedom to do things they liked. More than 90% of SDP participants said they were involved in making their own IPP. This tells us the program gave them a sense of freedom and confirmation.

### **3. SDP participants gave us more good news!**

When compared to people getting traditional services, they felt:

- Happier with the help they got planning their services and budgets.
- More like their services would help them have a good life.

Many participants looked at these positive changes in their lives as markers of more self-determination. Having more control over their lives helped them grow. They felt they were more self-aware, responsible, and independent. They also had better mental health, better connection with their communities, and better jobs.

### **4. Most SDP participants like and would recommend the program.**

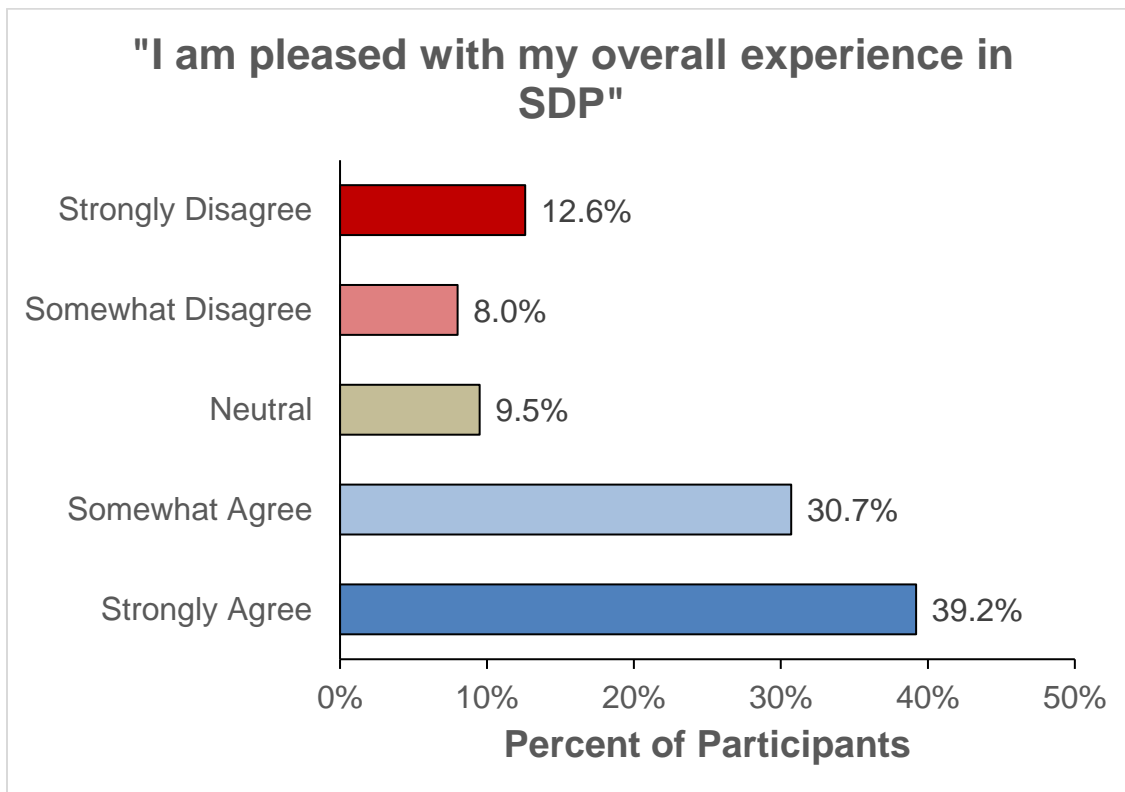
**77%** said they would recommend the SDP to others.

**70%** said they were happy with the SDP and its benefits.

They told us:

- They were happy to be in the program.
- The program was a good choice for them.
- The program was life changing.

**Graphic 1: *How Happy Participants are with the SDP***



**5. Participants want the SDP to be easier.**

The SDP participants liked many aspects of the program. But they also said there were things they did not like about the program. They said:

- Signing up is hard for participants and their families.
- Navigating the SDP is not easy. It takes a lot of time and effort.

They say these problems make the system unfair. Some people and their families have more time and experience in these areas. But others, especially from underserved communities, do not.

**6. Participants want more support in the SDP.**

Participants also wanted more support after signing up. They said it is hard to get information about the SDP and regional center staff often do not know much about the program. People not signed up for the SDP said it was hard for them to get information and support. This may be why they had not enrolled.

The answers from the surveys showed that some people did not understand who made decisions about their services and supports. Some participants also wanted more help with their budget and services.

Participants also mentioned other problems once in the program. Here are some examples.

- High regional center service coordinator turnover.
- Waitlists and poor customer service for financial management services.
- Not enough Independent Facilitators.

## **7. Some parts of the SDP are unfair.**

The focus group and open-ended survey participants said the SDP is unfair in some ways. Here are some examples.

- Decisions about budgets and services are different for different people.
- Signing up for the SDP might be more difficult for people who:
  - Lack support systems to guide them.
  - Do not speak English well.
  - Come from families with fewer supports, education, or other supports.

Our research showed significant differences for specific demographic groups.

## **8. Different experiences for participants that are Black, Indigenous, and People of Color (BIPOC).**

The people we connected with said BIPOC participants have different experiences with the SDP because of their race. BIPOC participants were less likely than White participants to:

- To have met their service coordinator.
- Talk about getting support from regional center staff.
- Have the same level of control over their person-centered plan.
- Be satisfied with the program.

BIPOC participants were somewhat more likely to report progress, growth, and positive outcomes related to the SDP on the open-ended survey. We think this means that the program was helpful for BIPOC participants who figured out ways around the obstacles.

**9. SDP is harder for younger participants.**

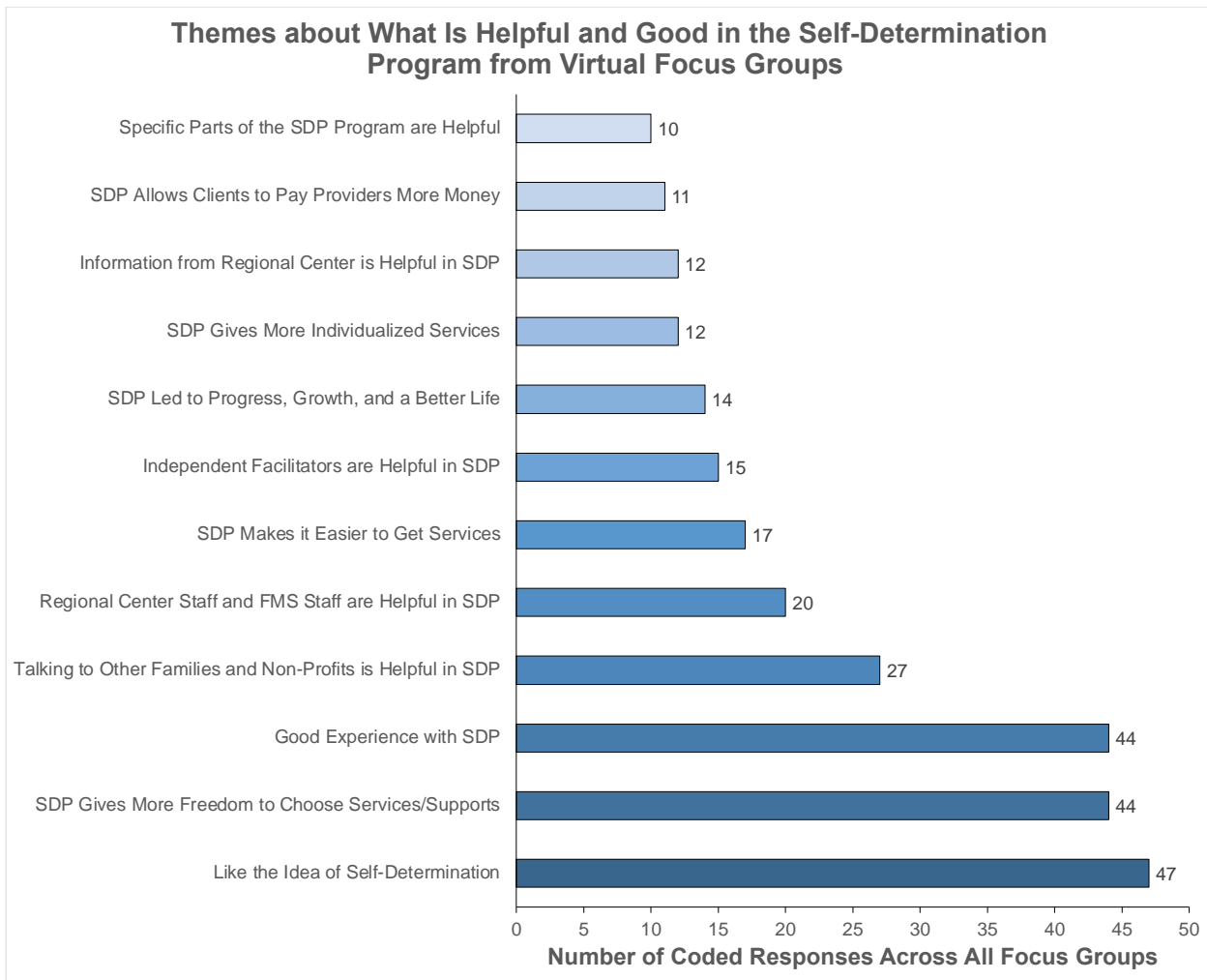
Family members who were helping relatives under 21 had twice as many challenges than adults did with the SDP. This is probably why this group was less likely to recommend the SDP to others.

**10. SDP is harder for autistic participants.**

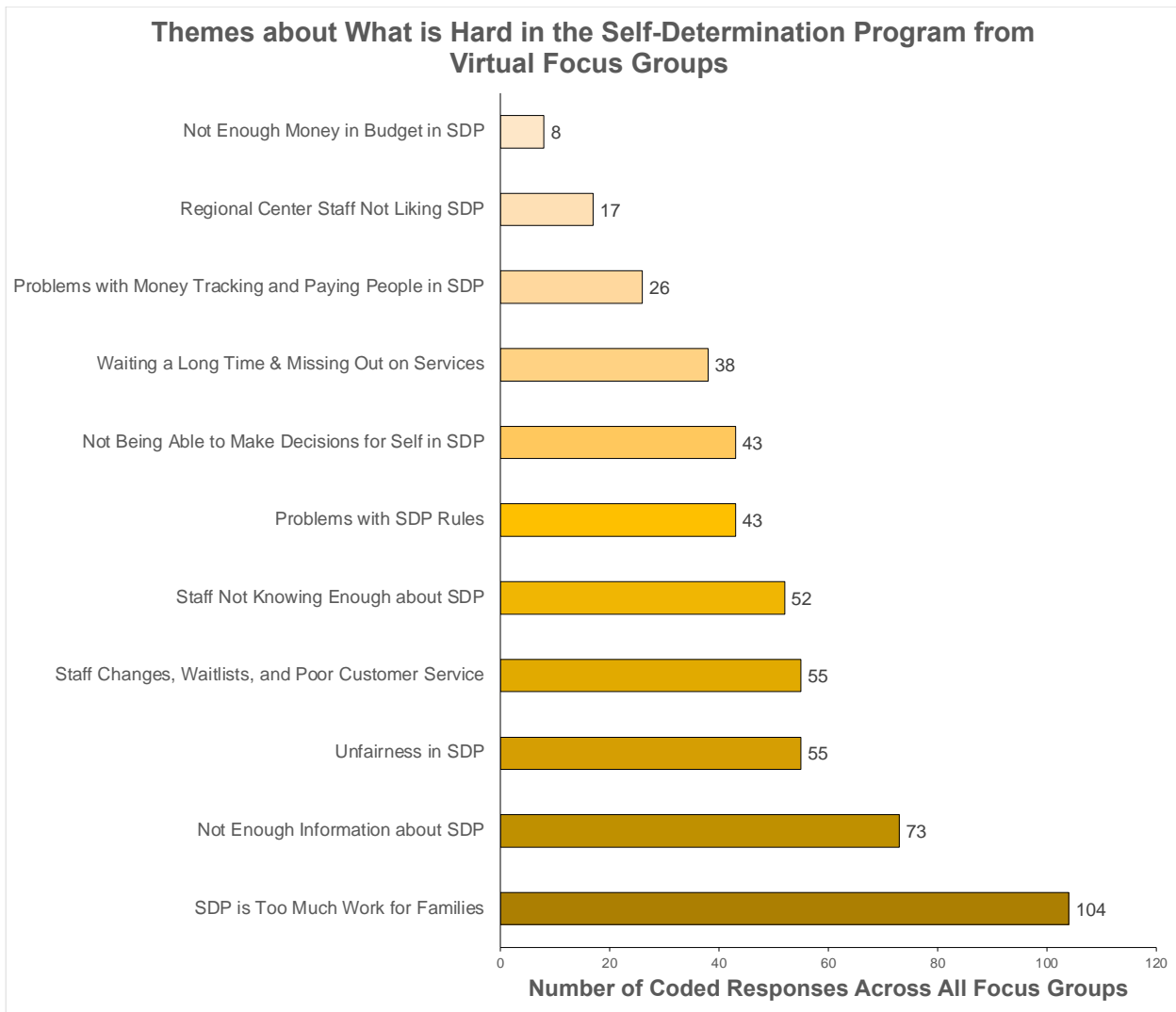
Both surveys showed that SDP participants with autism and their families had more challenges with the program than other diagnostic groups. It was harder for them to get information and deal with regional center and FMS staff. They felt less involved and were somewhat less satisfied than other groups.



## Graphic 2: *What Participants Liked about the Self-Determination Program*



### Graphic 3: *Problems with the SDP Discussed in the Virtual Focus Groups*



## **How to Improve the SDP**

Most SDP participants like the program, support its core values, and would recommend it to others. What they did not like was how hard it was to sign up for and how much work it took once they were in the program. We believe the changes below would improve many of the participants' current problems with the SDP.

### ***More Information about the SDP***

Regional centers should:

- Provide easy-to-understand and accessible information about the program.
- Improve capacity for peer-to-peer counseling about the SDP.
- Give information about the SDP to all clients during IPP meetings.
- Do outreach work with stakeholders and informal networks.

This would help clients and more people understand and talk about the program.

### ***Make it Easier to Sign Up for the SDP***

Participants said the SDP should:

- Make requirements and deadlines clear.
- Get rid of steps that are not required by law.
- Pay FMS vendors more.
- Ask DDS to check that all regional centers are following the same rules and processes to make it fair for all.

### ***Make Budgeting Easier***

All regional centers should calculate each client's budget using the same method. This will be fairer for all clients.

### ***Make Managing Services Easier***

The SDP could:

- Make it easier for clients to manage their services.

- Create better guidance on spending plans and give tools for finding service providers that all participants in the system can access. This will give clients, families, Independent Facilitators (IF), and regional center staff the same, updated, and easy-to-access information.
- Pay Independent Facilitators (IF) more before you sign up.
- Make Independent Facilitators (IF) easier to find for all.
- Use the SDP Ombudsman for more dedicated problem-solving support.

### ***Better Pay, Training & Recruitment for Independent Facilitators (IFs)***

- Set uniform standards for all Independent Facilitators.
- Recruit and train more Independent Facilitators, especially from underrepresented communities.
- Change the law so that SDP participants could receive a dedicated amount of money for an Independent Facilitator.

### ***Use the SDP as a Model to Improve Worker Recruitment, Hiring & Retention***

Use the flexibility of the SDP to create a model to hire and set rates for services. Data from the SDP program can be used to create pilot projects with new or innovative service types or service bundles. This could help us to increase the number of providers available for underserved groups.

### ***Make the System Fairer***

We can serve underserved communities better if we:

- Have more providers who are culturally competent and who speak languages other than English.
- Create systems that provide all participants and regional centers equal access to resources and services. (We may have to increase funding or incentives for providers in underserved areas.)
- Do outreach to understand what underserved communities in the SDP need.
- Work with DDS and the regional centers to explore ways to provide more support and providers to underserved communities.

## Future Research

The research for this report focused on the SDP participants' experiences. We recommend more research to:

- Get input from regional center staff about the SDP.
- Compare the experiences of different groups and their families, such as BIPOC participants, participants under 21, and autistic participants.
- Compare outcomes of the SDP participants and non-SDP participants.
- Study how features of the system impact the SDP.