

An Evaluation of Participant Experience in California's Self-Determination Program

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Prepared by:



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EXECUTIVE SUMMARY

Background

In October 2013, Governor Brown signed into law Senate Bill (SB) 468 (Emmerson) to create the Self-Determination Program (SDP) (Welfare and Institutions Code ([WIC] § 4685.8 et seq.). The Department of Developmental Services (DDS) implements the program, which included 2,688 participants as of April 2023. Beginning June 2018, the SDP became available at every regional center as an alternative way to receive services. The SDP provides clients and their families increased flexibility and choice, and greater control over decisions, resources, services, and supports. Through the SDP, participants are to experience more freedom, authority, support, responsibility, and confirmation in implementing their Individual Program Plan (IPP).

The SDP statute requires the State Council on Developmental Disabilities (SCDD), in collaboration with Disability Rights California (DRC), and the University Centers for Excellence in Developmental Disabilities (UCEDDs) at the University of Southern California (USC), University of California Los Angeles (UCLA), and University of California Davis (UCD), to issue a report in June 2023 on the status of the SDP. The report must include information about how the SDP is furthering the principles of the program and recommendations to enhance its effectiveness.

This report is different from prior reports on the SDP, as it is the most comprehensive engagement of SDP participants about the program utilizing research methods to-date. It emphasizes the voices, experiences, and recommendations of SDP participants and those closely involved in the program. It is driven by their insights, providing a valuable perspective that informs the findings and recommendations contained in this report.

Statement of Findings

People experienced with the SDP largely view the program favorably and would recommend it to others, even with the barriers they describe. The SDP is furthering the core principles of self-determination, and these principles and concepts of the program itself are what participants viewed most positively. The challenges described by participants largely fall into the administrative burdens that come along with the program. *In short, participants felt that the problem with SDP is not the concept or its principles, but the administrative burden in obtaining and keeping SDP enrollment.*

Methods

UCLA Tarjan Center UCEDD conducted the data collection between December 2022 and June 2023 and completed the data analysis in June 2023. In total, the program evaluation included 244 consumers, 314 parents/caregivers, 20 independent facilitators, and 14 other respondents (e.g., siblings, conservators) regarding their experiences with the SDP in California. The program evaluation was conducted in three phases. The first phase consisted of an online quantitative survey (completed by 242 people) administered through UCLA Qualtrics, that included items from the National Core Indicators® survey. The second phase consisted of virtual focus groups conducted on Zoom with various stakeholders (completed by 97 people). The third phase of the program evaluation invited stakeholders who were not selected for the focus groups to respond to the open-ended questions asked in the focus groups via a written, online qualitative survey (completed by 265 people).

Highlights of Results

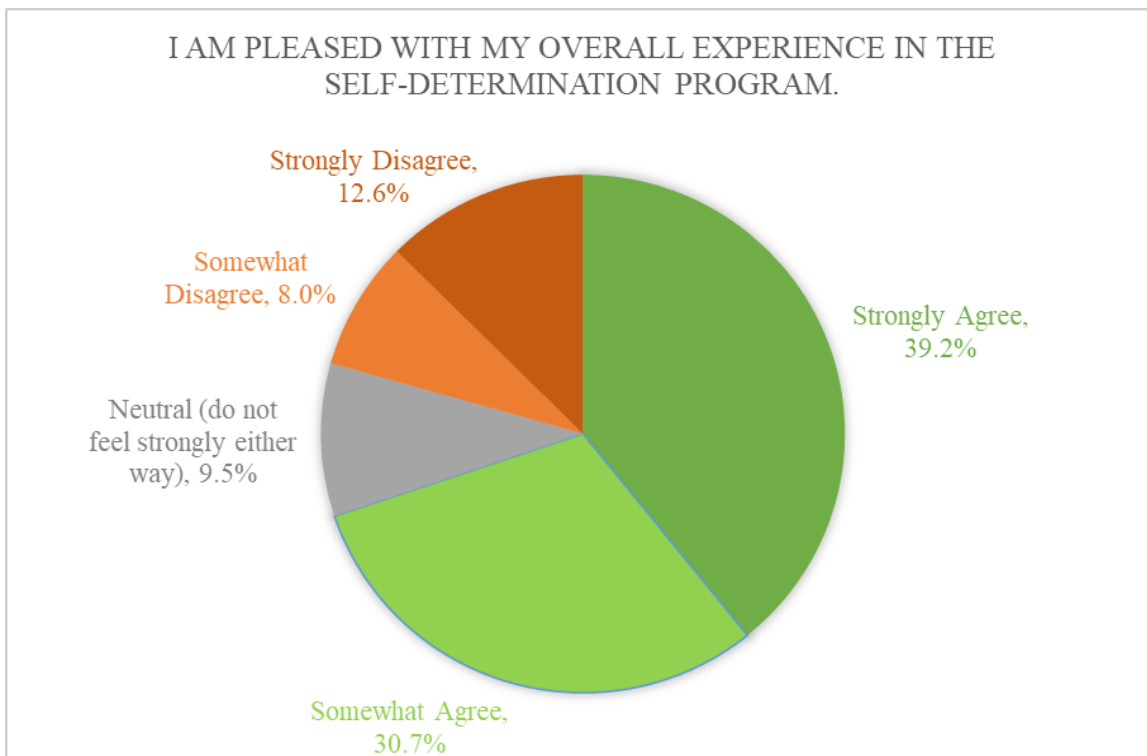
- 1. *Participants Support the Concept of the SDP:*** The idea that people with disabilities and their families should have the freedom and design to pursue their life paths, along with the supports of their choosing, received widespread agreement from participants in the focus groups and qualitative survey. The concept of the SDP inspired hope in them, and they expressed desire for the program to succeed to fully realize its potential.
- 2. *The SDP Furthers the Principles of Self-Determination:*** Across all three program evaluation phases, evidence demonstrated that the SDP furthered the principles of self-determination: freedom, authority, support, responsibility, and confirmation. Among the most frequently cited benefits of the SDP was the participants' newfound freedom and authority in choosing their own service providers and accessing personalized services beyond that of the traditional system. Qualitative results indicated that current SDP participants were more likely than those who were not enrolled to report on greater freedom, better service access, and being able to pay their providers better rates.

In the quantitative survey, the majority of SDP participants expressed satisfaction with their living arrangements and their ability to engage in enjoyable activities, indicating a strong sense of freedom. Further, over 90% of SDP participants reported involvement in the development of their IPP, further reinforcing the principle of confirmation. Results also highlighted advantages of the SDP over traditional services, as SDP participants were more likely to report adequate assistance in planning their services and budgets, as well as feeling that their services contribute to a good life, in comparison to participants in the traditional regional center system. These findings further exemplify the principles of self-determination.

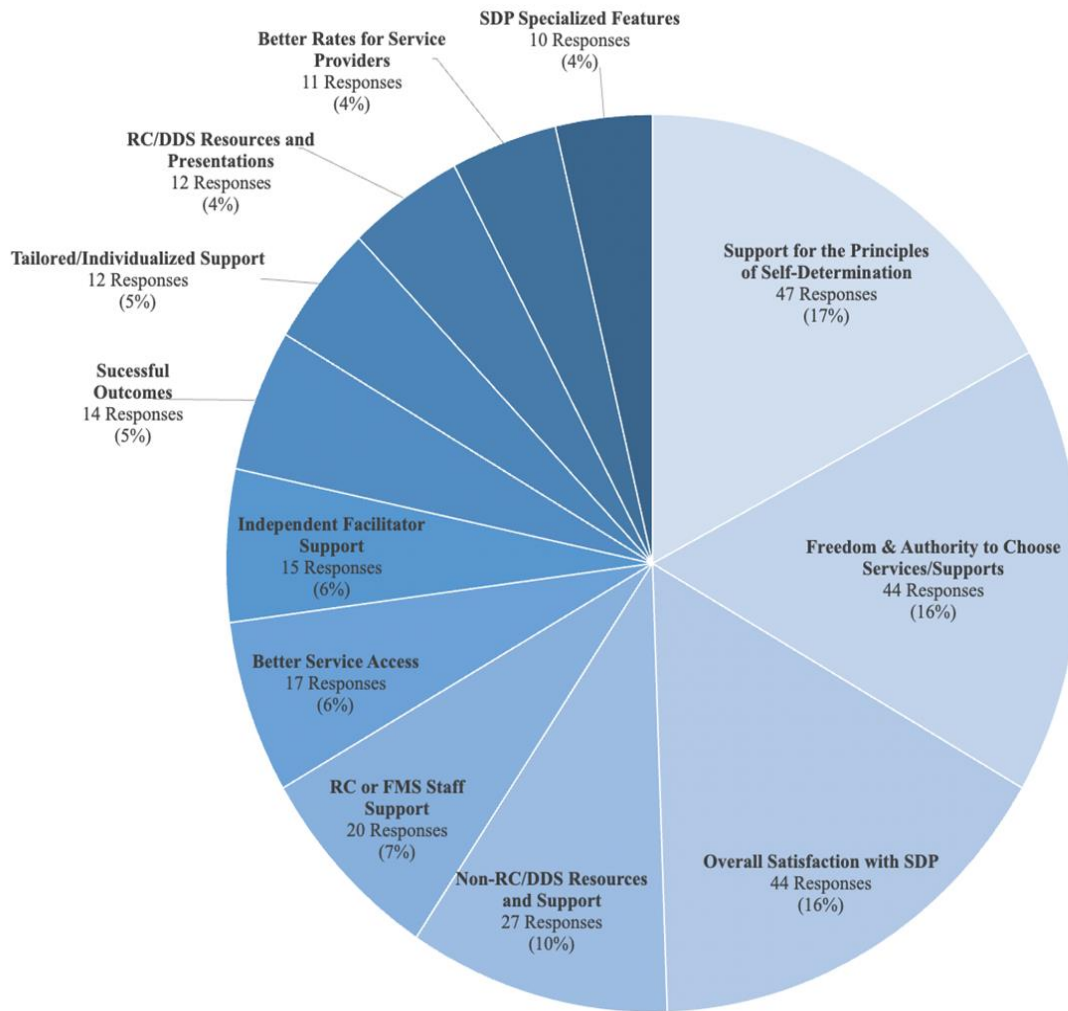
Many participants connected these advancements in self-determination to positive growth and progress in areas like self-awareness, responsibility, mental health, community integration, independence, employment, and quality of life.

3. Participants Endorse the SDP: Many participants endorsed the SDP, expressing their satisfaction and willingness to recommend the program to others. 70% of respondents were pleased with their experience in the program, while an even higher percentage (77%) would recommend the SDP to others. The open-ended responses highlighted that participants were glad to be in the Self-Determination Program and believed it was the right choice for them. Several participants described the program as “life-changing,” conveying an overall sense of satisfaction with the program and the benefits it has given them. For specific results related to satisfaction, helpful components, and positive outcomes of the SDP, please see Figures 1 and 2 from phases 1 and 2, respectively.

Executive Summary Figure 1. Satisfaction in the Self-Determination Program among Currently Enrolled Participants and Caregivers



Executive Summary Figure 2. Emergent Themes of Helpful Components and Positive Outcomes in the Self-Determination Program from Virtual Focus Groups

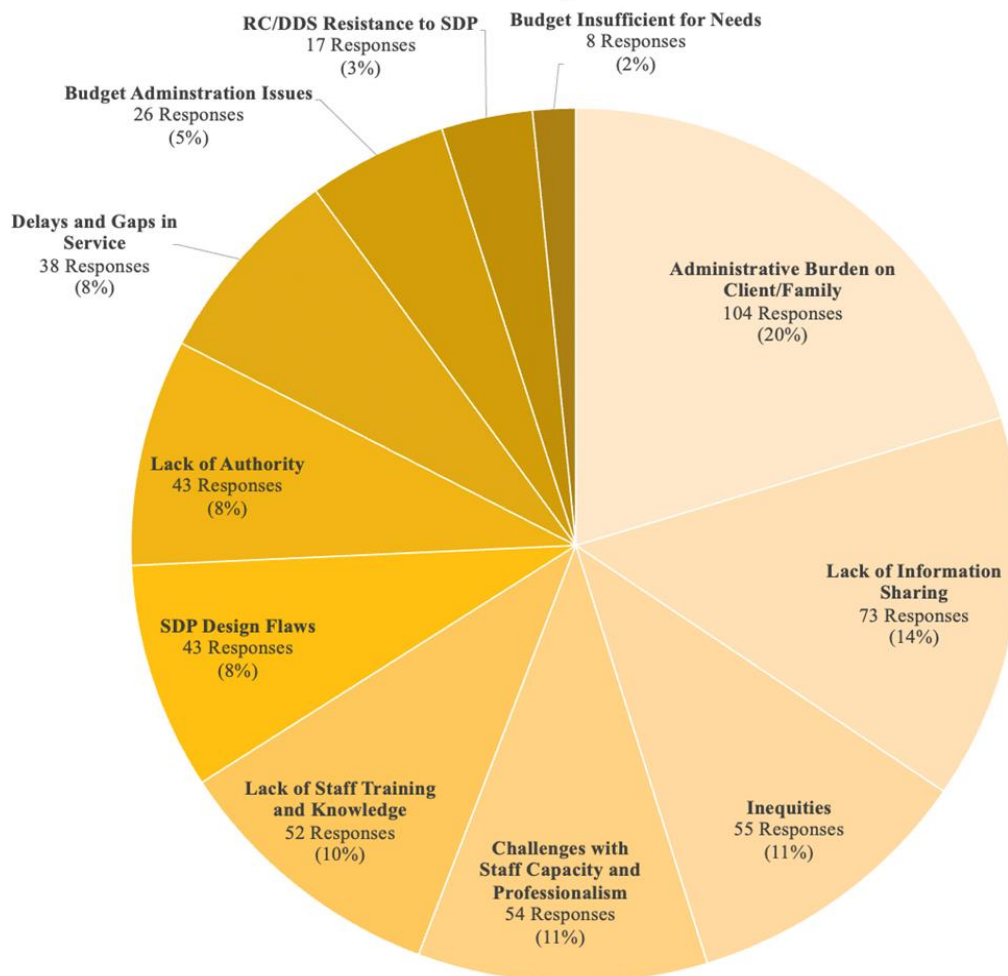


4. Participants Wish the SDP was Easier, with More Support: Despite numerous positive aspects, participants identified significant barriers and challenges with the SDP. Most prominently, participants thought the SDP could be improved by reducing complexity and administrative burden on the participant. Individuals and families perceived the enrollment process and ongoing navigation of the program as time-consuming, labor-intensive, and demanding. This was seen as an issue of inequity, as some individuals may not have the time or capacity to manage such requirements.

Additionally, participants expressed a lack of sufficient support throughout various stages of the SDP. Results suggested that information about and within the program is not readily available, with regional center staff often lacking comprehensive knowledge of the SDP. Findings show that individuals not currently enrolled in the SDP were more likely to express that they encountered difficulties enrolling and accessing sufficient information about the program, suggesting that a lack of accessible information about the SDP may be hindering

enrollment. The quantitative survey revealed participants' uncertainty in decision-making processes, relying heavily on others to make decisions about support networks and resource utilization. A sizeable minority of participants expressed a need for additional assistance in deciding how to utilize their individual budget and services. Qualitatively, individuals and families also described struggles with issues such as service coordinator turnover, waitlists and customer service related to Financial Management Services, and limited availability of Independent Facilitators. See Figure 3 for barriers and challenges that emerged in Phase 2.

Executive Summary Figure 3. Emergent Themes of Barriers and Challenges in the Self-Determination Program from Virtual Focus Groups



5. Inequities Within the SDP: Focus group and qualitative survey participants reported concerns about various forms of inequities within the program. These included racial disparities and disparities in how the SDP is being implemented across regional centers (e.g., differences in what services are approved, differences in budget). Participants also noted that the high level of complexity and administrative burden in the program made the SDP less accessible to individuals with developmental disabilities, participants for whom English is not their first language, and families with diverse socioeconomic and educational backgrounds. Further, statistical analyses revealed significant differences on the following dimensions for specific demographic groups:

- a. ***Less Support, Lower Satisfaction, yet Higher Positive Outcomes for BIPOC participants:*** Across both the quantitative and qualitative results, data suggests racial disparities. BIPOC (Black, Indigenous, and People of Color) participants were less likely to report meeting with their service coordinator and were less likely to describe receiving support from regional center staff. Furthermore, BIPOC participants reported significantly lower levels of control over their person-centered plan and lower levels of satisfaction with the program than White participants. One positive finding was that BIPOC participants were marginally more likely to describe achieving progress, growth, and positive outcomes through the SDP. These findings suggest that although a lack of support throughout the process may contribute to lower levels of satisfaction, those who persevered in the program experienced successful outcomes.
- b. ***The SDP is Harder to Navigate for Younger Participants:*** Family members representing minor aged clients were significantly more likely to encounter challenges in the SDP, with such themes occurring at a rate more than twice as often as adults. Higher rates of challenges may help explain the finding that respondents who were associated with participants under 21 were less likely to recommend the program.
- c. ***The SDP is Harder to Navigate for Autistic Participants:*** In both the quantitative and qualitative surveys, autistic participants and their family members reported more challenges navigating the SDP, including difficulties accessing information, challenges with staff, lower perceived levels of involvement in planning, and slightly lower satisfaction.

Recommendations

Based on the data above, people experienced with the SDP largely view the program favorably and would recommend it to others, even with the barriers to access they describe. The areas that were most positively viewed by participants are the principles and concept of the program itself. The challenges described by participants largely fall into the administrative burdens that come along with the program. *In short, participants felt that the problem with the SDP is not the concept or its principles, but the administrative burden.* To build on the promise of the SDP, we propose the following recommendations for changes in the administrative process to better facilitate the statutory goals of SDP for current and future participants.

- **Improve Access to Information about the SDP** by requiring regional centers to share information about the SDP with people who are new to the regional center system, and to offer SDP as a choice during the IPP planning process. We recommend enhancing outreach and awareness among informal networks, improving the capacity for peer-to-peer counseling about the SDP, and developing clear and accessible guidance materials.
- **Streamline the Enrollment Process** by eliminating steps that are not statutorily required, developing clear timelines and deadlines for each stage of the enrollment process, increasing Fiscal Management Services (FMS) provider rates, and strengthening the oversight of the role of DDS to ensure consistent application of rules and processes across regional centers to promote equity and fairness.
- **Streamline the Budgeting Process** by standardizing the process for determining individualized budget amounts to prevent discrepancies and remove subjective judgment of regional center staff.
- **Reduce Administrative Burden** among SDP participants by shifting obligations that are currently placed on individual participants, Independent Facilitators, and/or service coordinators and to systemwide functions by establishing clear guidance regarding spending plan expenditures, establishing a publicly available service provider directory, expanding the affordability and accessibility of Independent Facilitators, and enabling the SDP Ombudsperson office to provide more dedicated problem-solving support.
- **Improve Compensation and Capacity of Independent Facilitators** by establishing core competencies for Independent Facilitators (IF), investing in building an adequate network of Independent Facilitators with a focus on recruiting IFs from underrepresented communities, and modifying the SDP statute to allow Independent Facilitators' pay to be allocated as a specific line item when forming the SDP Budget.
- **Leverage SDP as a Model to Improve Workforce Recruitment, Hiring, and Retention** by using hiring and rate setting flexibilities found in the SDP to gather data on and develop pilot projects related to new or innovative service types or service code bundles, which may be more effective at increasing the number of providers available to serve traditionally underserved groups.

- ***Create a More Equitable System and Mitigate Disparities*** by tailoring supports to underserved communities by expanding the pool of providers who can meet the unique cultural and linguistic needs of these communities, by implementing measures to ensure equitable distribution of resources and services (such as increased funding or incentives for providers serving historically underserved areas) and by conducting targeted outreach campaigns and identifying how DDS and regional centers can build capacity to support underserved communities in the SDP.

Areas for Additional Research

This program evaluation also points to areas for additional research and policy development that were outside the original scope of the study, including:

- Perspectives of regional center service coordinators.
- Differences in barriers by demographic group, including differences for BIPOC, younger, and Autistic participants.
- Outcomes of people in SDP compared to people in traditional services.
- How certain systemic issues specifically affect SDP.

APPENDIX 1.

Virtual Focus Groups and Qualitative Survey Questions

Note: The questions below were asked of currently enrolled participants. Wording was adjusted depending on the participant type (e.g., participant, family member, independent facilitator) and current enrollment status.

1. What has been your experience with the Self-Determination Program?
 - a. This includes:
 - i. Making decisions in your own life
 - ii. Creating and managing your Individual Program Plan (also called your IPP)
 - iii. And overall thoughts about the program that you want to share.
2. What obstacles have you experienced at any time during the Self-Determination Program?
 - a. This includes:
 - i. The amount of control you have in how your funds are spent
 - ii. The choice you have in the services and supports you receive
 - iii. And anything else you want to share about the obstacles you experience in the Self-Determination Program.
3. What has been helpful about the Self-Determination Program? What have you been able to do within the Self-Determination Program that you were not able to do in traditional services?
 - a. This includes:
 - i. The amount of control you have in how your funds are spent
 - ii. The choice you have in the services and supports you receive
 - iii. And anything else you want to share about what has been helpful with the Self-Determination Program.
4. Do you feel like you have received enough support within the Self-Determination Program? What supports have been helpful? If your supports have not been helpful, what could be done differently to support you?
 - a. This includes your experience and who helped you:
 - i. Enroll in the program
 - ii. Develop the spending plan
 - iii. Identify services
 - iv. Create life goals
 - v. And anything else you want to share about the supports you received in the Self-Determination Program.
5. What suggestions would you make to improve the Self-Determination Program? What would you like to change and what would you like to keep?
 - a. This includes ways to improve:
 - i. The freedom to choose
 - ii. The authority to control how money is spent
 - iii. The supports received
 - iv. The ability to take responsibility for decisions about services and supports
 - v. The role of participants and families to make decisions
 - vi. Any other improvements you recommend for the Self-Determination Program.
6. Any additional comments you want to make about Self-Determination Program?