Voices of Self Determination

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

June 30, 2023

Prepared by:

CALIFORNIA SCDD
State Council on Developmental Disabilities

UCLA Tarjan Center

Disability Rights California
California's protection & advocacy system

Children's Hospital LOS ANGELES®

# TABLE OF CONTENTS

EXECUTIVE SUMMARY ........ 1

- Background ........ 1
- Statement of Findings ........ 2
- Methods ........ 2
- Highlights of Results ........ 2
- Recommendations ........ 9
- Areas for Additional Research ........ 10

FULL REPORT ........ 11

- Background ........ 11
- Self-Determination: A National Context of Self-Direction ........ 11
- Self-Determination in California ........ 12
- Current Participation in SDP ........ 13
- SDP and Equity ........ 15

Evaluation Methods ........ 17

- Phase 1: Quantitative Survey ........ 20
- Phase 2: Virtual Focus Groups ........ 21
- Phase 3: Qualitative Survey ........ 23

Evaluation Results ........ 23

- Quantitative Survey ........ 23
- Virtual Focus Groups ........ 35
- Qualitative Survey ........ 45

Discussion ........ 51

- Recommendations ........ 51
- Stage-Based Recommendations ........ 51
- Systems-Level Recommendations ........ 55
- Areas for Additional Research ........ 57

Conclusion ........ 58

Appendix Table of Contents ........ 59

> *“SDP is all about reaching your dreams and fulfilling them.”*
>
> *– Current SDP Participant*

# 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, proving a valuable perspective that informs the findings and recommendations contained in this report.

> *“It holds so much promise! … I believe [SDP is] the best path forward for the IDD community, but we have many potholes to fill and a lot of bumps still to navigate.”*
>
> *– Family member of a Current SDP Participant*

## 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.

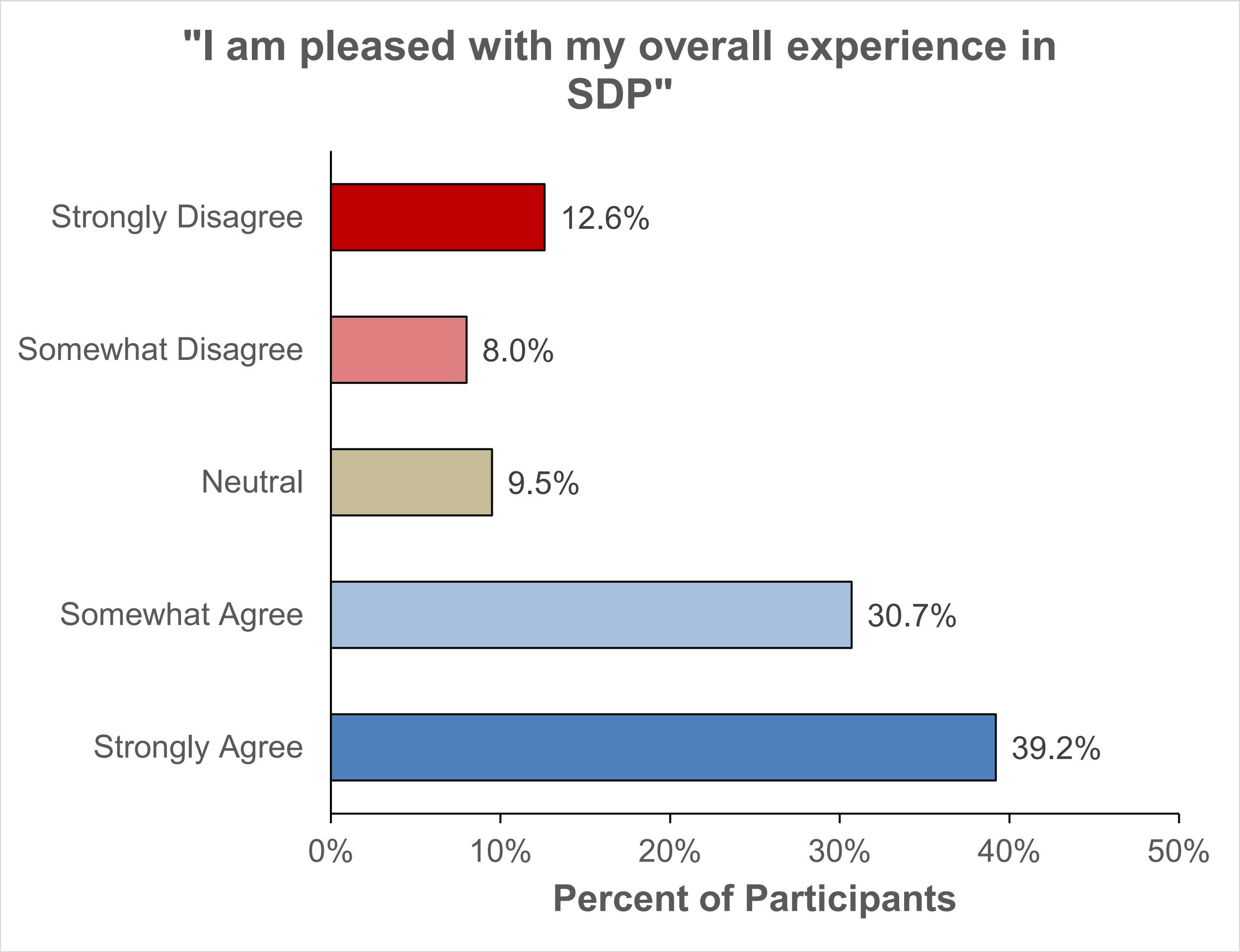
3. ***Participants Endorse the SDP:*** Many participants endorsed the SDP, expressing their satisfaction and willingness to recommend the program to others. 70% of respondents were pleased with their experience in the program, while an even higher percentage (77%) would recommend the SDP to others. The 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.

---

> *“With Self-Determination I have more freedom to choose who helps me get things done. My staff is now someone I trust and not a stranger… I love that I have a spending plan that I can see and understand.”*
>
> *– Current SDP Participant*

---

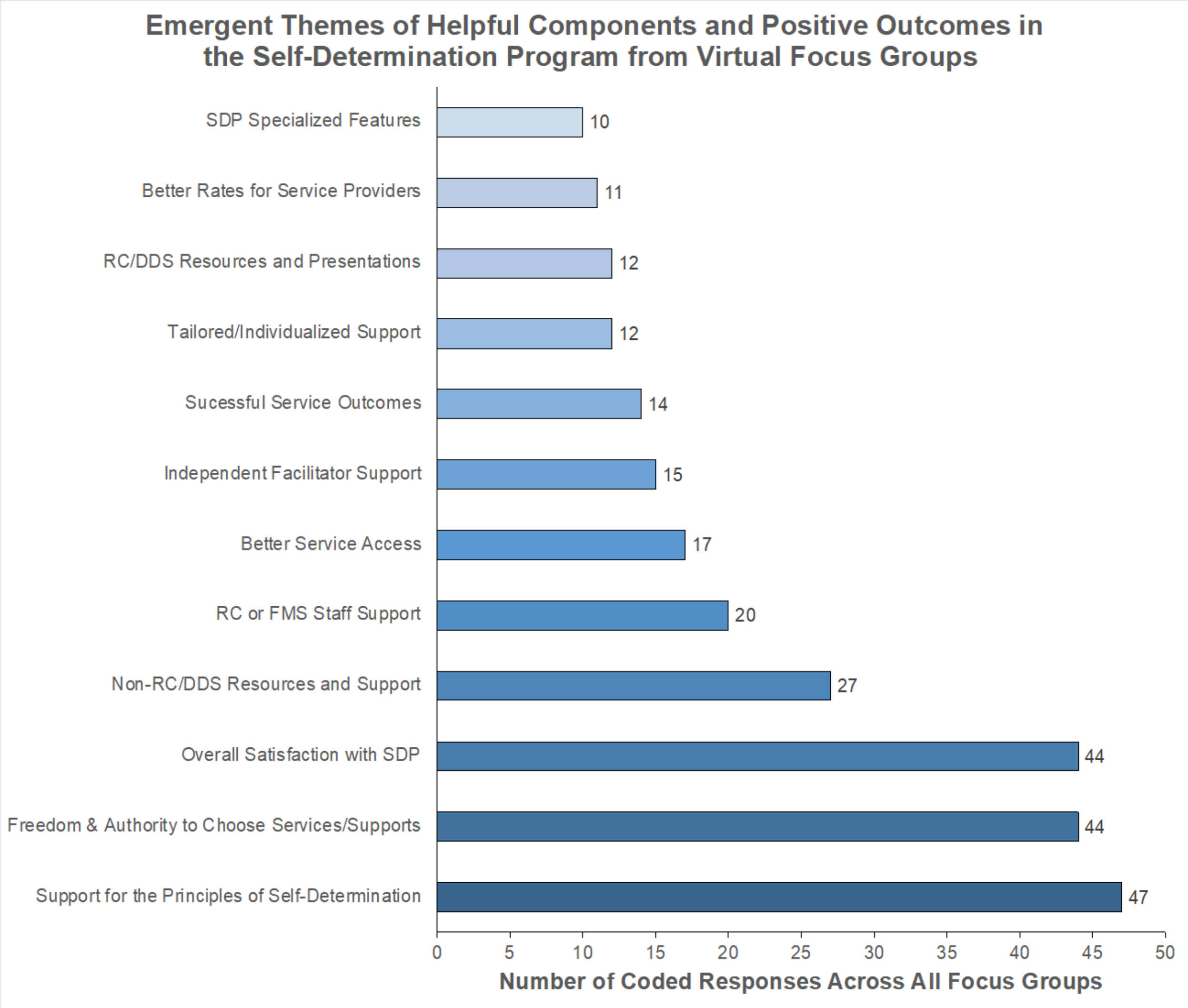
Executive Summary Figure 1. Satisfaction in the Self-Determination Program among Currently Enrolled Participants and Caregivers



> *"SDP has been life-altering… My son makes all of the decisions in his life now. He receives support doing the things he loves. He is taking a college course at the local junior college. He is working with supported employment and has had a paid internship at his favorite comic bookstore. He travels independently to hang out with friends. He is living a wonderful self-determined life and loving it."*
>
> *– Family member of a Current SDP Participant*

> *"I have the most freedom in meeting my educational and vocational goals I [have] ever had."*
>
> *– Current SDP Participant*

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



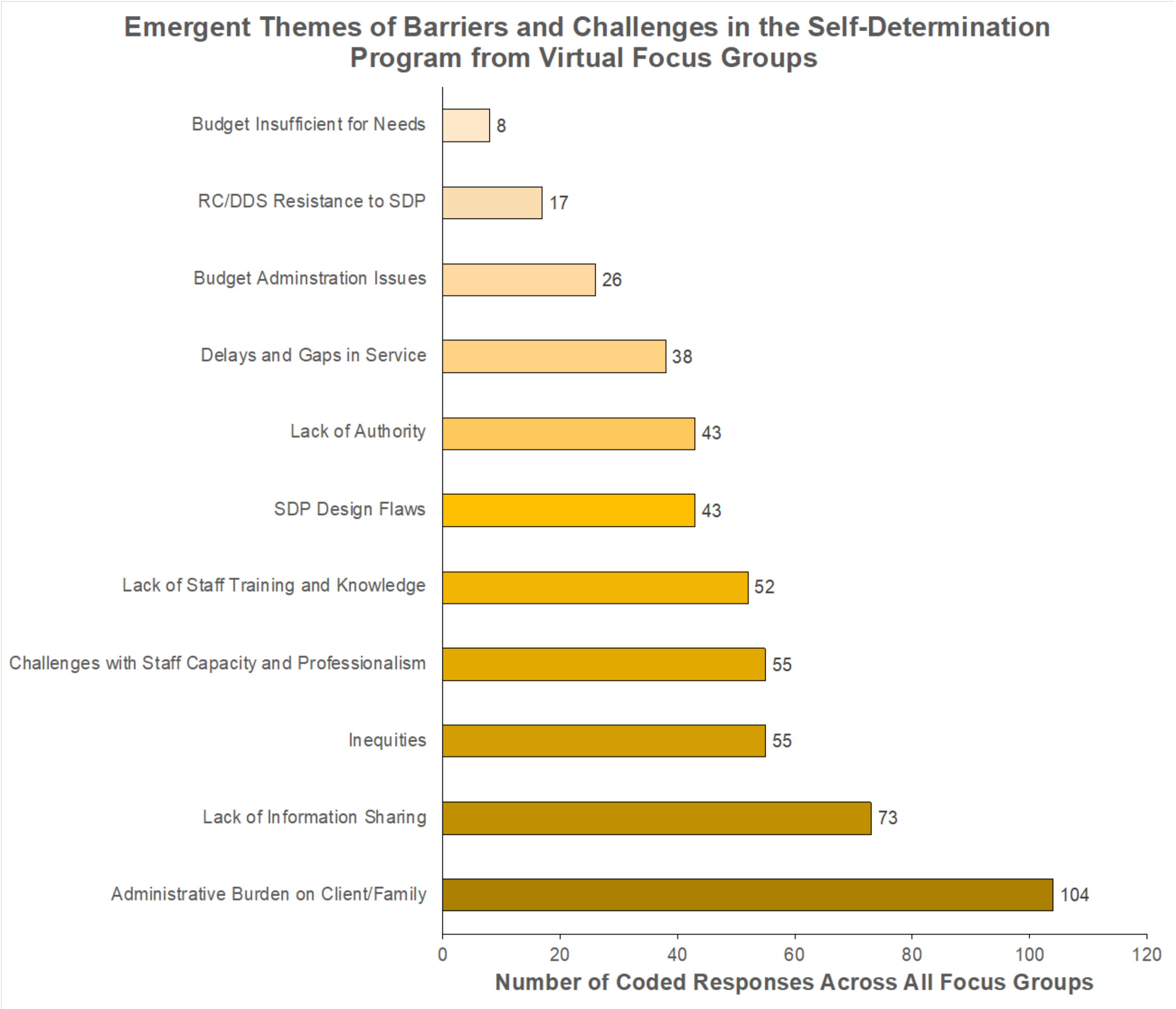
> *"With Self-Determination I have more freedom to choose who helps me get things done… I love that I have a spending plan that I can see and understand."*
>
> *– Current SDP Participant*

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.

> *"Parents are already overwhelmed… It is a lot to deal with all the steps to get the services and to chase down paperwork, spending plans, signatures and people at regional center should not be expected to. Simplify this process even more, somehow, some way."*
>
> *- Family member of a Current SDP Participant*

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



---

*"One thing that could be done differently is to provide more information about the program and the services available, which would help families make more informed decisions about their options. Additionally, more support could be provided to families during the transition to the program, which can be a challenging process."*

*- Family member of a Current SDP Participant*

---

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.

---

*“I really wish it was more of a one stop shop where you could get your services started and finalized in one agency…”*

*– Regional Center Client Interested in SDP*

---

## 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.

> *“…Having so many agencies and choices and decisions to make is confusing to myself and has made it difficult moving forward. I've been trying for over 2 years to finalize my enrollment.”*
>
> *– Regional Center Client Interested in SDP*

- ***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.

---

> *"[I am a] educated professional, able to reduce my work hours so I can keep this SDP going, and I am having a very hard time… How is this ever going to be accessible for non-native English speakers, [those] who can't afford to work less, [those] who may not have much support?"*
>
> *- Family member of a Current SDP Participant*

---

## 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.

# FULL REPORT

## 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). 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 SDP, participants are to experience more freedom, authority, support, responsibility, and confirmation in implementing their Individual Program Plan (IPP).

The SDP statutes says 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), is to issue this report in June 2023 on the status of the SDP (WIC § 4685.8(y)(2)-(3)). This report is to include how the SDP is furthering the principles of the program and recommendations to enhance the program's effectiveness. This report may also include participant satisfaction and other measures when data is available.

## Self-Determination: A National Context of Self-Direction

Individuals with disabilities have a civil right to receive long-term services and supports in their own homes and in the community rather than institutions.[1] This civil right aligns with the preferences of most individuals with disabilities and older adults to receive services at home rather than in a congregate facility.[2] As services shift from nursing homes and congregate institutions into individual homes, individuals with disabilities have more control over their services. This principle of autonomy is foundational to disability rights more broadly and underpins the movement towards self-directed home- and community-based services (HCBS). Disability rights advocates in the 1960s developed this model to best tailor the supports they need to their desires for how they want their lives to look.[3]

---

[1] *Olmstead v L.C.* (98-536) 527 U.S. 581 (1999)

[2] Harrel, R., J. Lynott, S. Guzman, et al. "What Is Livable? Community Preferences of Older Adults." AARP Public Policy Institute, Washington, DC: April 2014. https://www.aarp.org/ppi/issues/livable-communities/info-2015/what-is-livable-AARP-ppi-liv-com.html

[3] National Council on Disability. "The Case for Medicaid Self-Direction: A White Paper on Research, Practice, and Policy Opportunities." National Council on Disability, Washington, DC: May 22, 2013. https://ncd.gov/publications/2013/05222013A

Today, states can develop a “self-directed” option using a Medicaid waiver, most commonly a 1915(c) waiver, which allows the state Medicaid agency to target the program to a select group of Medicaid beneficiaries.[4] Every U.S. state offers at least one self-directed HCBS option, but not all states have this option for individuals with intellectual and developmental disabilities (I/DD).[4]

In daily life, self-directed services allow an individual with I/DD, or a trusted person who they designate, to have a higher degree of control over their HCBS. The consumer can choose who to hire and fire, how many hours they work, and how much to pay them, within the restricted budget outlined by their state’s program. Further, many self-directed HCBS programs offer opportunities for individuals to customize their services to align with their values, hobbies, and interests. Self-directed services offer a degree of autonomy and flexibility that is not present in mainstream HCBS. However, this autonomy comes with a large responsibility to coordinate one’s own care.

## Self-Determination in California

Each state operates self-directed waiver programs differently. In California, the SDP serves as the self-directed option for people with I/DD.

The SDP for individuals with I/DD in California has a rich history that spans several decades. The program's foundation lies in the Lanterman Developmental Disabilities Services Act, which was enacted in 1969 and emphasized principles of person-centered planning, community integration, and self-determination. Since its inception, the SDP has undergone significant legislative milestones that have shaped its current form. The initial pilot program, established in 1998, paved the way for subsequent expansions and refinements.

In 2013, SB 468 (Emmerson) established the SDP as an ongoing initiative within the state's developmental disabilities service system. This legislation firmly established the self-directed practices of self-determination, like individual choice and person-centered planning, as core tenets of the program. The SDP gives participants flexibility and control over the services in their IPP. One way the SDP does this is by giving participants a budget to purchase services from direct service professionals. Participants have the freedom to hire providers not vendored by regional centers. Participants also have the responsibility to stay within their budget.

The SDP involves the collaboration of various agencies and entities to ensure its successful implementation. The California Department of Developmental Services (DDS)

---

[4] Edwards-Orr, M., M. Morris, C. DeLuca, et al. “National Inventory of  Self-Directed Long-Term Services and Supports Programs.” AARP Public Policy Institute, Washington, DC: September 2020. https://www.longtermscorecard.org/~/media/Microsite/Files/SelfDirection%20Promising%20Practices%20and%20Emerging%20Trends_Sept%202020.pdf

implements the SDP, which results in its function as the overseeing body, providing guidance, establishing program guidelines, and monitoring compliance. The State Council on Developmental Disabilities (SCDD) is an independent state department that advocates for the rights and inclusion of individuals with developmental disabilities and aims to ensure that the Self-Determination Program aligns with the needs and interests of participants. The SCDD oversees the Statewide Self-Determination Advisory Committee (SSDAC) which is an integral component of the Self-Determination Program. Regional centers, 21 nonprofit organizations contracted by the DDS, directly contribute to program enrollment and participant support by coordinating services for people with IDD. Local Volunteer Advisory Committees (LVAC) provide community oversight of the SDP implementation at each regional center. SDP participants are required to use a Financial Management Service (FMS) provider to assist with payments and financial records. Independent Facilitators (IF) can be volunteers or hired by participants to support their decision-making and person-centered planning processes. Additionally, various community agencies and other organizations offer a wide range of supports and services to participants.

The SDP in California is guided by principles outlined in state law. These principles aim to empower individuals and their families with increased freedom, control, and responsibility in selecting services and supports to achieve their IPP objectives. Participants in the SDP have the freedom to make their own decisions, plan their lives, and choose their own supports. They are granted the authority to allocate and spend their SDP budget according to their needs. Participants can also select the necessary support and services to reach their personal goals, including the option to hire support staff. With this freedom and authority, participants become responsible for managing their SDP budget and are accountable for the expenditures made on their behalf by their chosen FMS provider.

The SDP state law also identifies the following five principles of self-determination: freedom, authority, support, responsibility, and confirmation. These principles reflect the program's commitment to promoting self-determination and person-centered planning for individuals with developmental disabilities in California.

The SDP confirms the importance of empowering individuals and their families to make decisions that shape their life's journey and provides flexibility to select the range of support and services that align with their IPP goals.

## Current Participation in SDP

The SDP was made available in all regional centers in June 2018. Over the course of three years, during an initial phase-in period from June 2018 to June 2021, a total of 2,500 participants statewide had the opportunity to participate in SDP. In July 2021, the program expanded to include all regional center consumers living in the community. As of April 30, 2023, there are 2,688 regional center consumers enrolled in the SDP. Figures 5 and 6 illustrate age and disability demographic descriptions of SDP enrollees in April 2023.

Figure 5. Self-Determination Participants by Age, April 2023

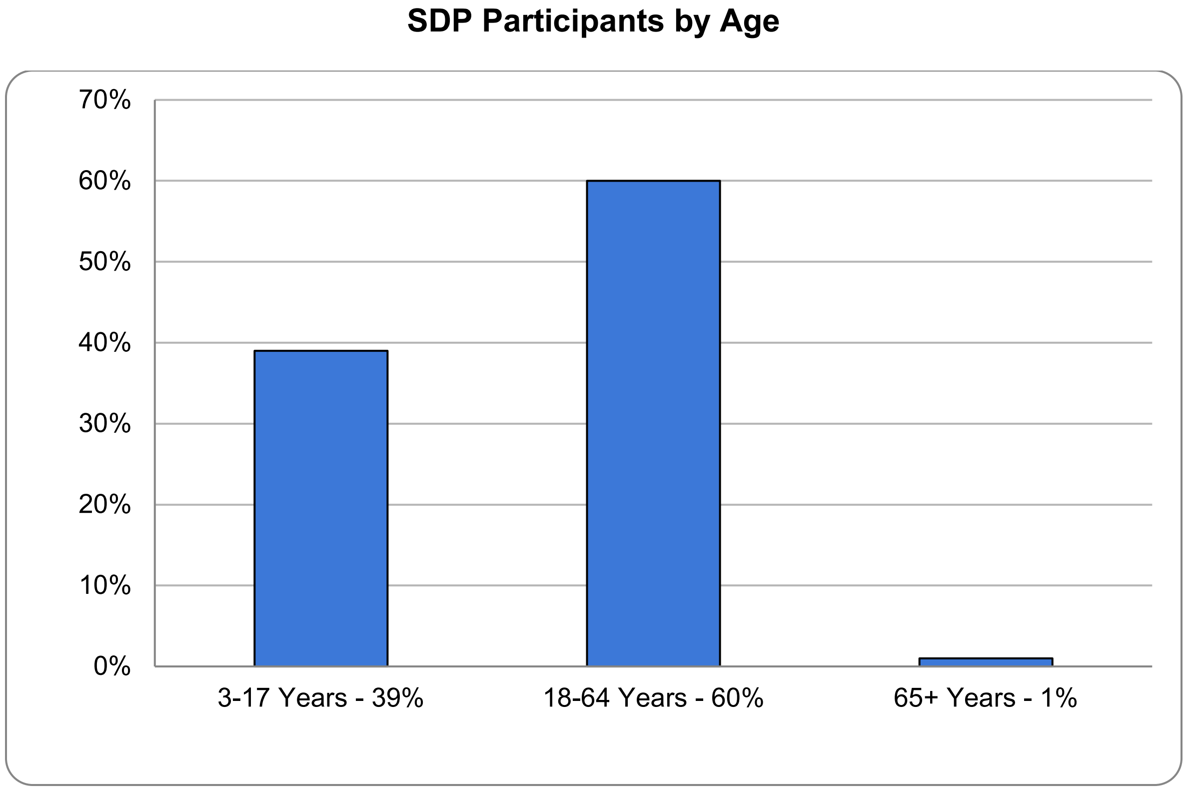
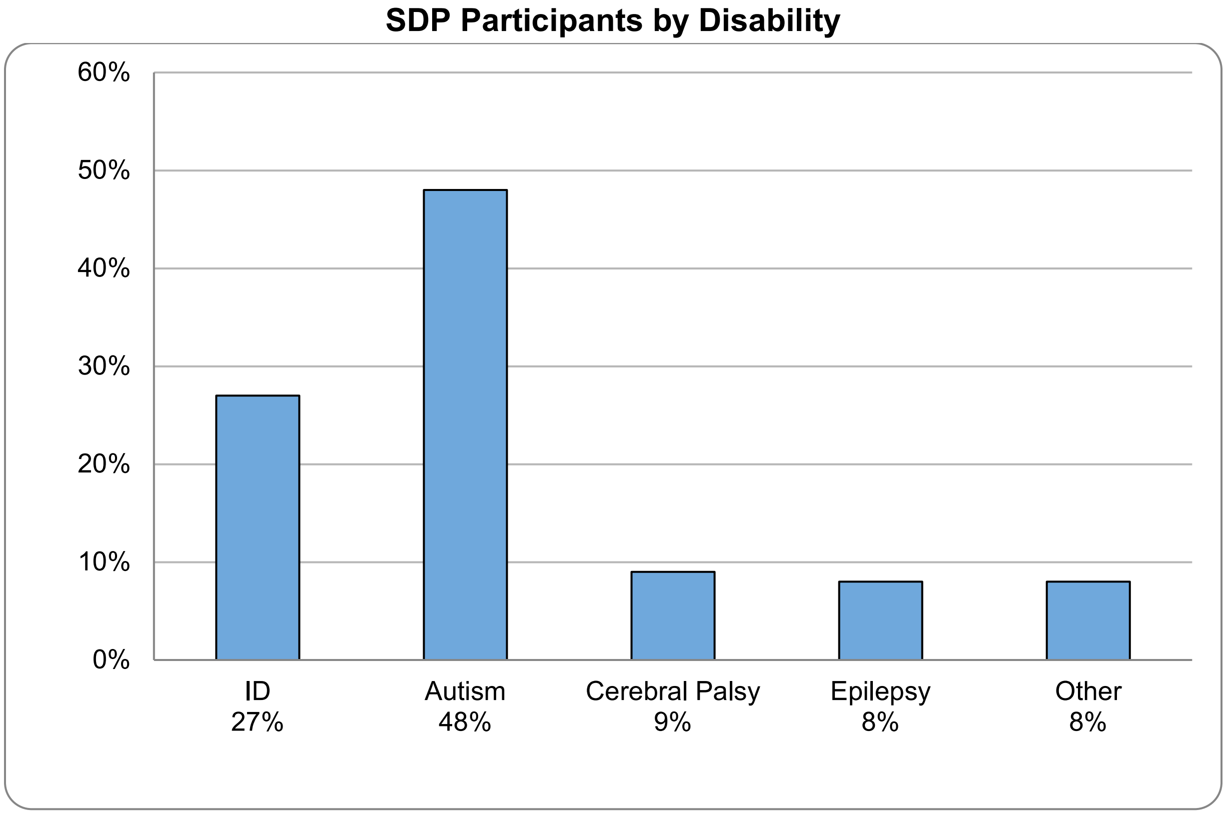


Figure 6. Self-Determination Participants by Disability, April 2023



## SDP and Equity

The SDP holds the potential to address the needs of historically underserved and unserved communities by providing equitable access to services that cater to the diverse needs of all communities. However, BIPOC participants report lower rates of support and satisfaction as highlighted in the findings of this report. The below figures contain the ethnic and language demographic descriptions of SDP enrollees as of April 2023.

Figure 7. Self-Determination Participants by Ethnicity, April 2023

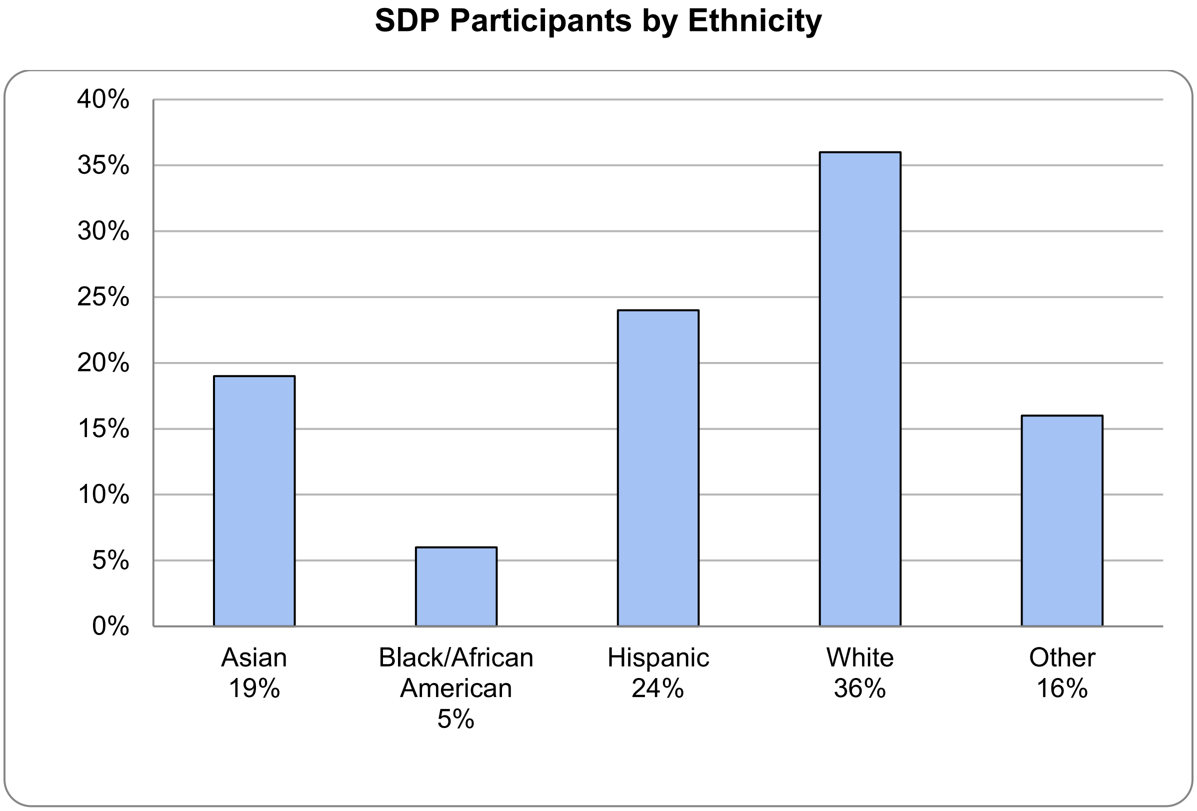
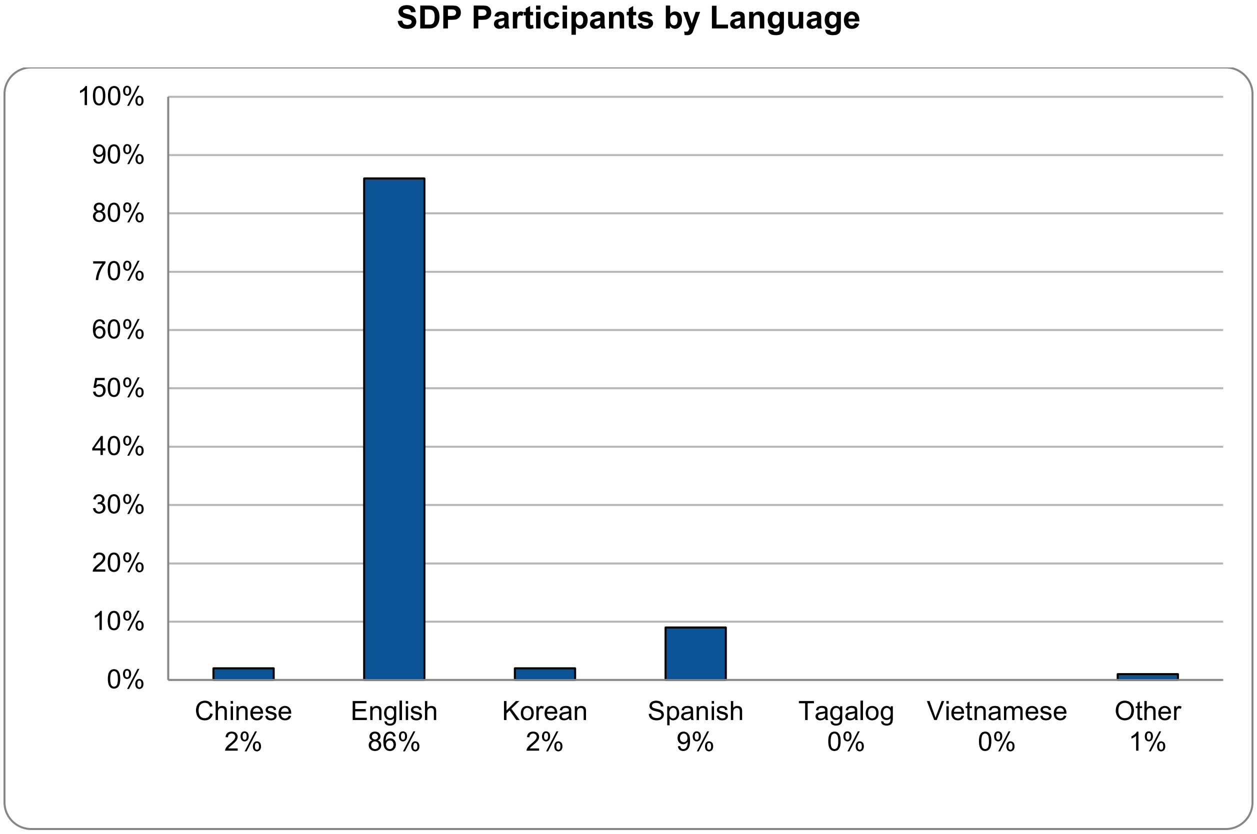


Figure 8. Self-Determination Participants by Language, April 2023



By allowing participants to design and manage their own services, the SDP offers a promising avenue for historically underserved and unserved communities to have services tailored to their specific needs. For instance, communities that have faced barriers due to cultural, linguistic, or geographic factors can potentially benefit from the SDP's flexibility to select providers who understand their unique cultural backgrounds or are located within their communities. At its core, the SDP is an equity program.

However, despite the program's potential, the current reality highlights a concerning disparity in access and supports in the SDP among historically underserved and unserved communities. It is crucial to examine the underlying factors contributing to this widening disparity.

One underlying cause for these disparities is the administrative burden of the existing system. Administrative burdens are the impacts or costs that people experience when interacting with government agencies, particularly in processes that feel overly complicated or confusing to citizens trying to access public services[5]. Prior research demonstrates that

---

[5] Moynihan, D., P. Herd, and H. Harvey, "Administrative Burden: Learning, Psychological, and Compliance Costs in Citizen-State Interactions," *Journal of Public Administration Research and Theory* 25 (1) (2015): 43–69, available at https://doi.org/10.1093/jopart/muu009

administrative burdens disproportionately affect communities of color, specifically in the context of Medicaid-funded programs and those that serve people with disabilities.[6] Although self-direction inherently requires a certain level of administrative work, the current complexity of the system disadvantages people of color, who could potentially benefit immensely from the program. These findings are consistent with a 2018 study on state self-directed programs for people with intellectual and/or developmental disabilities which identified the following as being among the key barriers to self-direction: administrative concerns about the volume and complexity of paperwork, confusion or difficulties in implementing a new service delivery model, with a lack of clear policies, leadership and training opportunities as important factors in confusion about, or opposition to, self-direction, and individuals with intellectual/developmental disabilities not being adequately informed, supported or empowered to self-direct.[7]

# EVALUATION METHODS

The Self-Determination Program (SDP) in California is designed to empower participants by giving them greater control and choice over their own services and supports, while promoting the self-determination and independence of individuals with disabilities. This evaluation of the SDP aimed to understand the program's achievements, identify areas for improvement, and further its development by examining its effectiveness and impact.

The program evaluation was conducted in three phases. The first phase consisted of an online quantitative survey (*n* = 242), 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 (*n* = 97). The third phase of the program evaluation allowed stakeholders who were not selected to be part of the focus groups to respond to the open-ended questions asked in the focus groups in a written, online qualitative survey (*n* = 265). In total, the program evaluation included 604 contacts with stakeholders regarding their experiences with the SDP in California. See Table 1 for demographic characteristics of participants across all three phases of the program evaluation.

---

[6] Schweitzer, J., E. DiMatteo, N. Buffie. "How Dehumanizing Administrative Burdens Harm Disabled People." Washington, DC: Center for American Progress, 2022. https://www.americanprogress.org/article/how-to-address-the-administrative-burdens-of-accessing-the-safety-net/; https://www.cbpp.org/research/health/states-can-reduce-medicaids-administrative-burdens-to-advance-health-and-racial

[7] Wilke, S., J. Wagner, F. Erzouki, et al. "States Can Reduce Medicaid's Administrative Burdens to Advance Health and Racial Equity." Washington, DC: Center on Budget and Policy Priorities, July 19, 2022. https://www.cbpp.org/research/health/states-can-reduce-medicaids-administrative-burdens-to-advance-health-and-racial

Table 1. Demographic Characteristics of SDP Program Evaluation Participants.

| | Quantitative Survey | Virtual Focus Groups | Qualitative Survey | Total Program Evaluation |
|---|---|---|---|---|
| **Total Number of Participants** | 242 | 97 | 265 | 604 |
| | | | | |
| **Self-Determination Program Enrollment[1]** | | | | |
| *Enrolled* | 84.4% (200) | 44.7% (38) | 62% (158) | 69% (396) |
| *Not Enrolled* | 15.6% (37) | 55.3% (47) | 38% (97) | 31% (181) |
| **Respondent Type** | | | | |
| *Self* | 38.8% (90) | 45.2% (43) | 41.8% (111) | 41% (244) |
| *Parent/Caregiver* | 55.2% (128) | 44.3% (42) | 54.4% (144) | 53% (314) |
| *Other* | 6% (14) | | | 2% (14) |
| *Independent Facilitator* | | 10.5% (10) | 3.8% (10) | 3% (20) |
| **Participant Diagnosis[2]** | | | | |
| *Intellectual Disability* | 23.8% (62) | 37.9% (36) | 47.5% (121) | 28% (219) |
| *Autism* | 54.4% (142) | 41.1% (39) | 54.5% (139) | 42% (320) |
| *Epilepsy* | 5.7% (15) | 14.7% (14) | 14.9% (38) | 9% (67) |
| *Cerebral Palsy* | 9.2% (24) | 12.6% (12) | 16.1% (41) | 10% (77) |
| *Other Disabling Condition* | 6.9% (18) | 13.7% (13) | 21.6% (55) | 11% (86) |
| **Participant Age** | | | | |
| *0-17 years old* | 63.9% (149) | 18.5% (17) | 14.6% (36) | 35% (202) |
| *18-30 years old* | 33.9% (79) | 52.2% (48) | 63% (155) | 49% (282) |
| *31+ years old* | 2.2% (5) | 29.3% (27) | 22.4% (55) | 15% (87) |
| **Race/Ethnicity[3]** | | | | |
| *American Indian or Alaska Native* | 0.4% (1) | 5.3% (5) | 2.7% (7) | 2% (13) |
| *Asian* | 15.2% (35) | 10.5% (10) | 5.8% (15) | 10% (60) |
| *Black or African American* | 7% (16) | 12.6% (12) | 30.2% (78) | 18% (106) |
| *Hispanic, Latinx, or Spanish Origin* | 21.7% (50) | 28.4% (27) | 10.5% (27) | 18% (104) |
| *Middle Eastern, Arab, or North African* | 2.6% (6) | 4.2% (4) | 0.8% (2) | 2% (12) |
| *Native Hawaiian or Other Pacific Islander* | 0% (0) | 4.2% (4) | 2.7% (7) | 2% (11) |
| *Multi-Racial* | 10.9% (25) | 4.2% (4) | 5% (13) | 7% (42) |
| *White* | 40.9% (94) | 34.7% (33) | 40.7% (105) | 40% (232) |
| *Other* | 1.3% (3) | 1.1% (1) | 1.6% (4) | 1% (8) |
| **Gender[3]** | | | | |
| *Male* | 63.9% (149) | 37.9% (36) | 44.8% (116) | 51% (301) |
| *Female* | 33.9% (79) | 55.8% (53) | 52.1% (135) | 46% (267) |
| *Gender Diverse* | 2.2% (5) | 6.4% (6) | 3.1% (8) | 3% (19) |

| | | | | |
|---|---|---|---|---|
| **Preferred Language** | | | | |
| *English* | 93.5% (201) | 89.5% (85) | 94.3% (250) | 93% (536) |
| *Spanish* | 6% (13) | 8.4% (8) | 4.2% (11) | 6% (32) |
| *Chinese* | 0% (0) | | 1.1% (3) | 0.6% (3) |
| *Korean* | 0.5% (1) | | 0.4% (1) | 0.4% (2) |
| **Affiliated Regional Center**[4] | | | | |
| *Alta California Regional Center* | 9.2% (21) | 9.8% (9) | 7.3% (17) | 9% (47) |
| *Central Valley Regional Center* | 4.4% (10) | 0% (0) | 1.3% (3) | 2% (13) |
| *Eastern Los Angeles Regional Center* | 3.1% (7) | 3.3% (3) | 4.3% (10) | 4% (20) |
| *Far Northern Regional Center* | 3.9% (9) | 1.1% (1) | 3.4% (8) | 3% (18) |
| *Frank D. Lanterman Regional Center* | 3.9% (9) | 12.0% (11) | 15% (35) | 10% (55) |
| *Golden Gate Regional Center* | 4.4% (10) | 4.3% (4) | 3.8% (9) | 4% (23) |
| *Harbor Regional Center* | 6.1% (14) | 4.3% (4) | 6% (14) | 6% (32) |
| *Inland Regional Center* | 8.3% (19) | 8.7% (8) | 4.7% (11) | 7% (38) |
| *Kern Regional Center* | 3.5% (8) | 0% (0) | 1.7% (4) | 2% (12) |
| *North Bay Regional Center* | 0.9% (2) | 3.3% (3) | 1.3% (3) | 1% (8) |
| *North Los Angeles County Regional Center* | 6.1% (14) | 6.5% (5) | 6% (14) | 6% (33) |
| *Redwood Coast Regional Center* | 1.3% (3) | 0% (0) | 1.7% (4) | 1% (7) |
| *Regional Center of Orange County* | 7% (16) | 4.3% (4) | 3.4% (8) | 5% (28) |
| *Regional Center of the East Bay* | 5.3% (12) | 3.3% (4) | 5.1% (12) | 5% (28) |
| *San Andreas Regional Center* | 8.8% (20) | 5.4% (5) | 4.7% (11) | 7% (36) |
| *San Diego Regional Center* | 7.9% (18) | 6.5% (6) | 8.5% (20) | 8% (44) |
| *San Gabriel/Pomona Regional Center* | 2.2% (5) | 1.1% (1) | 0.4% (1) | 1% (7) |
| *South Central Los Angeles Regional Center* | 3.9% (9) | 13% (12) | 15.8% (37) | 10% (58) |
| *Tri Counties Regional Center* | 2.2% (5) | 1.1% (1) | 0.9% (2) | 1% (8) |
| *Valley Mountain Regional Center* | 3.5% (8) | 3.3% (3) | 0.9% (2) | 2% (13) |
| *Westside Regional Center* | 3.9% (9) | 8.7% (8) | 3.8% (9) | 5% (26) |

---

[1] In surveys in which independent facilitators responded, they were removed from the breakdown of enrolled and not enrolled in the Self-Determination Program. For all demographics, percentages are calculated from valid data.

[2] Participants with more than one diagnosis were counted in all diagnostic categories they identified. As such, these numbers will sum to a number larger than the total sample size.

[3] For the quantitative survey, participants were asked the race/ethnicity and gender of the program participant. For the virtual focus groups and qualitative survey, race/ethnicity and gender of the respondent (e.g., regional center client, caregiver, or independent facilitator) was collected.

[4] Respondents with affiliation with more than one regional center were excluded for clarity. Regional center affiliation for the focus groups and qualitative survey was determined by reported zip code.

## Phase 1: Quantitative Survey

The first phase of the program evaluation included a comprehensive survey aligned with the principles of the SDP to examine participant satisfaction, access to information and resources, and adherence to the five principles of self-determination – freedom, authority, support, responsibility, and confirmation – within the program. To inform survey development, items were drawn from the National Core Indicators® (NCI®) In-Person Survey and NCI® Adult Family Survey (National Core Indicators®, 2012), a national initiative to measure and improve the performance of government-run agencies that serve individuals with developmental disabilities and their families. The NCI® surveys are intended to respect the independence, individuality, and self-determination of people with developmental disabilities and produce actionable insights that can be used to improve services and supports for this population. NCI® questions were reviewed, selected, and adapted as needed to maximize understanding of how the SDP is furthering the five principles of self-determination, while minimizing time burden on survey respondents. Additional questions that are specific to the SDP in California were added (e.g., enrollment in and satisfaction with the program).

To reach stakeholders, a flyer advertising the opportunity to participate in the survey was mailed to families who, per Department of Developmental Services (DDS) records, had an association with the SDP (e.g., enrolled, previously enrolled, attended orientation). The flyer included a QR code to access the survey and translations detailing how to participate in 10 different languages: Arabic, Armenian (Eastern), English, Farsi, Hmong, Korean, Simplified Chinese, Spanish, Tagalog, and Vietnamese. Twenty survey respondents were randomly selected in a lottery to win $25 dollar Amazon gift cards for their participation. The quantitative survey was completed by 242 participants, including 200 individuals that were currently enrolled in the program.

### *Statistical Analysis of Quantitative Survey*

Descriptive statistics, including frequencies and percentages, were calculated to summarize the distribution of responses for each survey item. To allow for a clearer understanding of participants' perspectives and enhance statistical power, questions with 5-point Likert scales were condensed into three categories for data analysis: "Agree," "Neutral," and "Disagree." Short answer responses to questions, including "If you were previously enrolled in the Self-Determination Program and are no longer enrolled, please explain why," were summarized. Chi-square tests were used to compare ratings of stakeholders who were SDP participants to those not currently enrolled in the program to determine whether the program improved outcomes for people with developmental disabilities. Chi-square tests also explored whether there were differences in the participant experience while in the SDP program by respondent type (self-respondent vs. caregiver/parent), race (BIPOC [Black, Indigenous, and People of Color] vs. White), age (21 years and older vs. under 21 years of age), gender (female vs. male), and diagnosis (ASD vs. all other reported diagnoses).

## Phase 2: Virtual Focus Groups

In an effort to understand first person narratives and lived experiences with the SDP, focus groups were conducted with 5 stakeholder groups: 1) regional center clients who were enrolled in the SDP, 2) family members of regional center clients who were enrolled in the SDP, 3) regional centers clients who were not enrolled in the SDP (i.e., previous participants and interested participants), 4) family members of regional centers clients who were not enrolled in the SDP (i.e., previous participants and interested participants), and 5) Independent Facilitators working with the SDP. A total of 9 focus group sessions were held on afternoons or evenings in April 2023 (between 4:00-7:00 PM PDT). Focus groups were organized according to stakeholder group, with two focus group sessions each for groups 1-4 and one focus group session for independent facilitators.

Focus group questions were developed through collaboration with the UCLA Tarjan Center, which is a University Center for Excellence in Developmental Disabilities (UCEDD), Disability Rights California (DRC), the State Council on Developmental Disabilities (SCDD), individuals with disabilities and other stakeholders. Questions were open-ended, centered around overall experience with the program, and included barriers, benefits, supports received, and improvements needed (e.g., "*What suggestions would you make to improve the Self-Determination Program?*"). Each question included a follow up prompt that aligned closely with the five principles of self-determination to encourage participants to consider multiple aspects when answering (e.g., "*This includes ways to improve: the freedom to choose, the authority to control how money is spent, the supports received, the ability to take responsibility for decisions about services and supports, the role of participants and families to make decisions, and any other improvements you recommend for the Self-Determination Program*").

Notifications about the opportunity to participate in virtual focus groups were distributed via email, social media, and listservs by the UCLA Tarjan Center, DRC, SCDD, and other community partners in an effort to reach organizations and agencies serving people with disabilities, resource centers, professionals, and individuals with disabilities and their family members. Interested participants completed a pre-enrollment survey which included questions about their relationship with the Self-Determination Program, demographic characteristics, and their availability for pre-selected focus group times. Over 1,500 people completed the pre-enrollment survey.

Among those that completed the pre-enrollment survey, approximately 100 participants were selected to attend 9 separate focus group sessions (~11 participants per group). Participants were required to be 18 years of age or older and to have a valid California zip code. Participants were selected intentionally to best represent the California regional center population.[8] Demographic considerations in selection included: race/ethnicity,

---

[8] Department of Developmental Disabilities Fact Book Fiscal Year 2019-2020 18th Edition. www.dds.ca.gov. Published 2022. https://www.dds.ca.gov/wp-content/uploads/2022/11/FactBook-18th-Edition-Final-De-ID.pdf

language preference, gender, age, diagnosis, and region. A total of 97 participants attended the virtual focus groups. Female focus group participants were more highly represented due to the high proportion of female-identifying participants in the family member focus groups (e.g., more mothers than fathers participated).

Focus groups were facilitated by a member of the UCLA Tarjan Center and a member of DRC. Eight of the nine focus groups were supervised by a licensed clinical psychologist from the UCLA Tarjan Center. All focus groups offered live closed captioning, and five focus groups offered live simultaneous Spanish interpretation with closed captioning in Spanish. During focus group sessions, facilitators shared PowerPoint slides with participation instructions and questions as a visual aid to enhance comprehension. All focus group materials, including focus group questions, were evaluated and vetted for plain language by self-advocates with developmental disabilities. Participants were able to respond to questions verbally or via the chat. Participants were compensated with a $50 Amazon gift card for their time and participation. Please see Appendix A for questions asked in each stakeholder group during the virtual focus groups. Focus groups were recorded, with the chat and captioning transcripts saved and analyzed for themes.

### *Coding and Analysis of Virtual Focus Groups*

Focus groups were analyzed using qualitative coding methods, which enable responses to be grouped into common ideas and sentiments, called "themes." In some instances, participant responses to questions were coded for multiple themes. Responses to focus group questions were reviewed by the UCLA Tarjan Center team who generated a preliminary set of themes using inductive analysis, in which the data (i.e., focus group participants' responses) guided the creation of themes.[9] The coding team was supervised by a doctoral level researcher with extensive experience in qualitative coding; coders reviewed and coded the focus groups by listening to the recorded session content, reading the chat responses, and reviewing the transcripts. Revisions, additions, and refinements were made to themes during coding of the first three focus groups until the thematic coding system was finalized. All nine focus groups were then independently coded by both members of the coding team. Disagreements were resolved via consensus discussion to maximize accuracy. After this process, the frequency of themes was tallied within each stakeholder group as well as across all focus group participants to determine the most commonly reported themes. Thematic frequency provides insight into the most relevant and salient shared experiences.

---

[9] Azungah, T. (2018). Qualitative research: deductive and inductive approaches to data analysis. Qualitative Research Journal, 18(4), 383-400 https://doi.org/10.1108/QRJ-D-18-00035

## Phase 3: Qualitative Survey

Focus group questions were translated into 10 different languages: Arabic, Armenian (Eastern), English, Farsi, Hmong, Korean, Simplified Chinese, Spanish, Tagalog, and Vietnamese. Following the virtual focus groups, the focus group questions were incorporated into five UCLA Qualtrics surveys across the five stakeholder groups (see above), to allow written responses to the open-ended questions. Participants were invited by email to complete the survey if they 1) completed the focus group pre-enrollment survey, 2) did not attend the virtual focus groups, and 3) listed a California zip code in the pre-enrollment survey. The written qualitative survey was live for three weeks, and three reminder emails were sent after the initial invitations. Ten participants were randomly selected to receive a $50 Amazon gift card after the survey closed. In sum, 265 valid surveys were received and analyzed. Fifteen responses were received in languages other than English and were translated into English for analysis.

### *Coding and Analysis of Qualitative Survey*

Written survey responses were deidentified and coded for themes by two doctoral level researchers and a predoctoral psychology intern at the UCLA Tarjan Center. Thematic categories that emerged from live focus groups were applied, with additional codes added to best represent written responses. All surveys were independently coded by one researcher and then reviewed by a second researcher to ensure accuracy and consistency. In addition to reporting the frequency of each theme, analysis also utilized Chi-square and t-tests to examine group differences in response characteristics and the presence of themes by program enrollment, participant type, and demographic characteristics. In addition, beyond seeking solutions to barriers that emerged, specific recommendations for SDP improvements by focus group participants and qualitative survey respondents were aggregated to further inform development of the current report's recommendations.

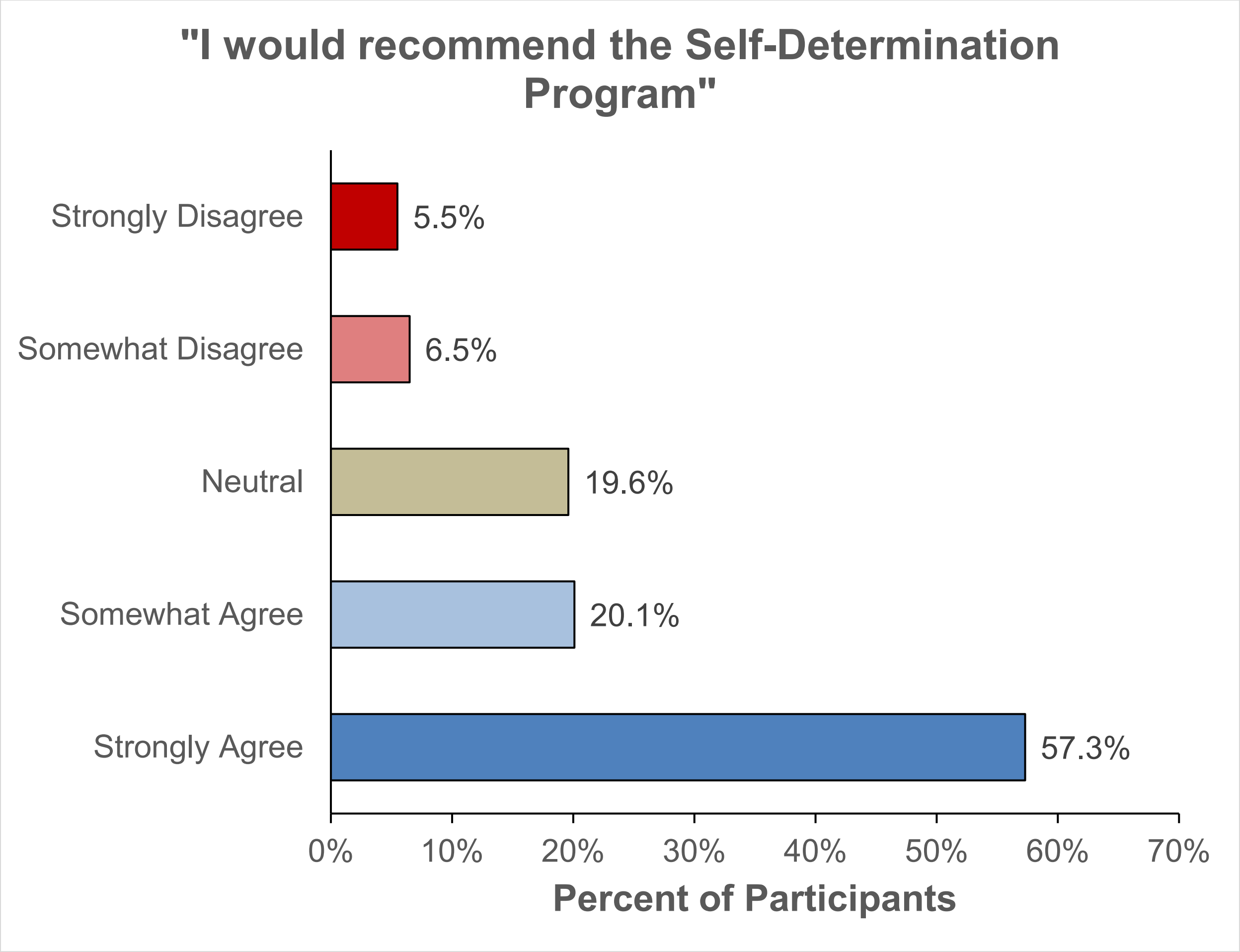
# EVALUATION RESULTS

## Quantitative Survey

### *Enrollment and satisfaction*

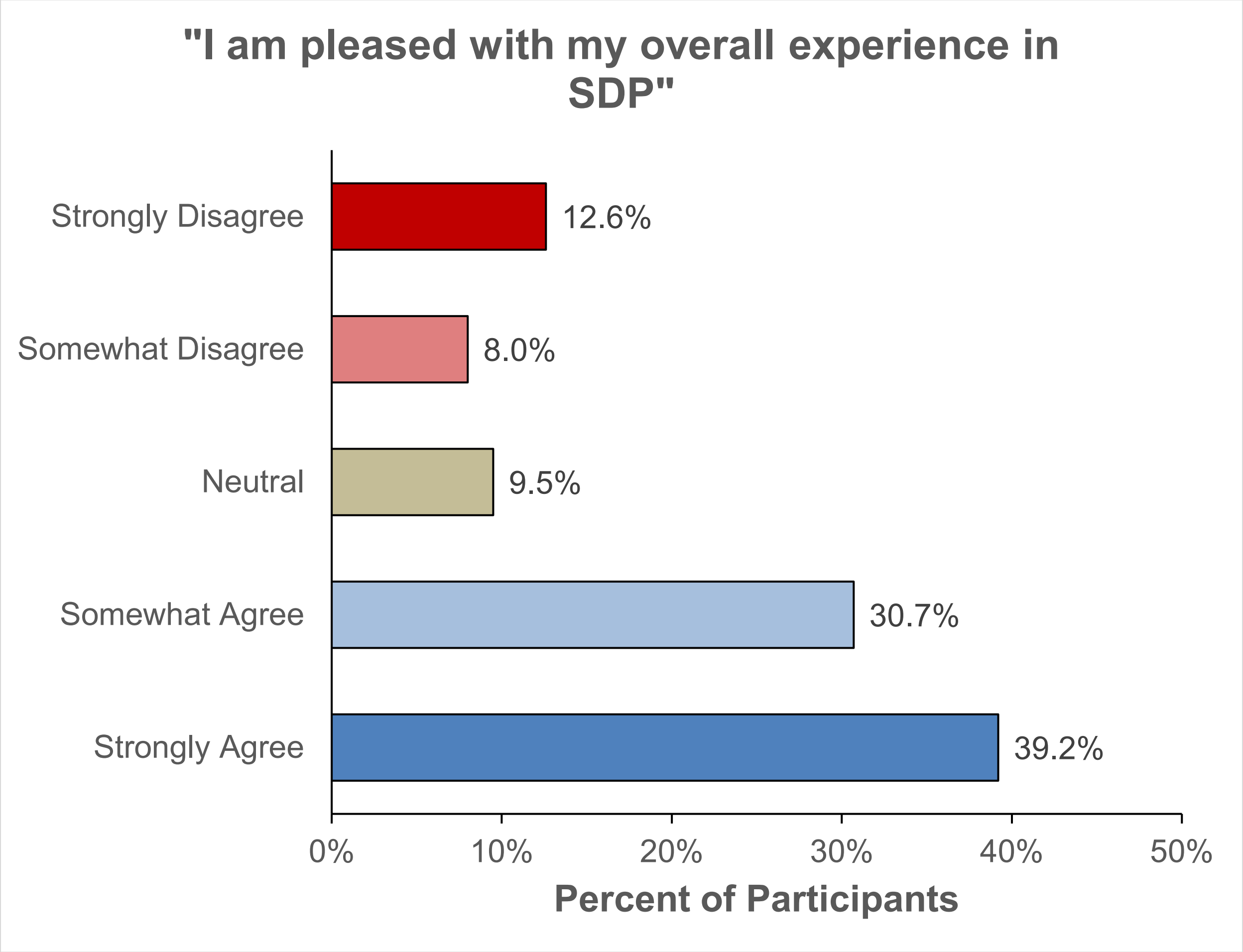
Regarding the sources through which respondents heard about the SDP, the most common channels were service coordinators (32.8%) and word of mouth (23.4%). Smaller percentages of respondents learned about the program through referrals (7.4%), advertisements (5.5%), social media (5.1%), and internet searches (3.1%). A notable proportion (22.7%) indicated "other" sources, which included personal connections such as friends and family, regional centers, advocacy groups, conferences, being part of the initial pilot program, and receiving information through emails or mail from regional center outreach.

Figure 1. Endorsement of the Self-Determination Program among Currently Enrolled Participants and Caregivers



> *"My services [in SDP] better meet my needs than the vendors through the traditional model. I feel confident that I can trust that my workers will provide appropriate and consistent services based on my needs. … SDP has improved my quality of life. I'm receiving the in home and community support I need."*
>
> *– Current SDP Participant*

Figure 2. Satisfaction in the Self-Determination Program among Currently Enrolled Participants and Caregivers



Regarding the statement about satisfaction with their experience in the program, the majority of the current SDP participants (69.9%) expressed some level of positive agreement. On the other hand, 20.6% disagreed with this statement, suggesting dissatisfaction, and 9.5% had a neutral stance. Analyzing group differences within SDP participants, a significant disparity in satisfaction was observed by race. Specifically, among BIPOC SDP participants, 63.3% agreed with being satisfied with the overall experience, while a greater proportion (79.8%) of White respondents expressed agreement, $\chi^2 = 6.01$, $p = .049$. No other group differences were evident.

Among current participants in the SDP program, the majority (77.4%) expressed positive agreement when asked if they would recommend the program. Conversely, 12.1% disagreed with this statement, and 10.6% had a neutral stance. When examining group comparisons among current SDP participants, a statistically significant difference was found by age. Specifically, respondents for SDP participants under the age of 21 were less likely to recommend the program (19.4% disagreed with recommending SDP) than respondents for SDP participants who were 21 years old or older (6.2%), $\chi^2 = 8.20$, $p =$

.017. This suggests a lower level of satisfaction among families of younger SDP participants. These findings highlight the role age and race play in shaping the opinions of and experiences in the SDP.

### ***Lessons from those who left the SDP***

There were 20 survey respondents who reported being previously but no longer enrolled in the SDP. Based on the responses provided by these 20 participants, the reasons for no longer pursuing or being enrolled in the SDP can be grouped into four themes. The first theme, *Administrative Issues*, includes delays caused by the pandemic shutdowns. The second theme, *Service Provider or Regional Center Factors*, highlights issues specifically related to service providers or regional centers. Examples include challenges with service providers attending meetings and lack of support during the transition to the SDP. Additionally, staff changes in the service coordinator role and a lack of clarity and guidance from the service coordinator made the process more difficult for some individuals. Negative experiences and challenges with the regional center were also mentioned as reasons for withdrawal. The third theme, *Other Reasons*, encompasses various factors. Some participants reported that their needs were already being met with traditional regional center services and providers, leading them to forgo participation in the SDP. Finally, some participants made a personal decision to withdraw from the program for reasons not specified. The final theme, *Lack of Knowledge/Information*, encompasses reasons related to participants' uncertainty or lack of understanding regarding their enrollment status or program details. Some participants mentioned not knowing what SDP means, indicating a lack of awareness about the program itself and perhaps confusion about whether they were enrolled. These findings highlight the multifaceted nature of reasons for discontinuation in the SDP. Addressing administrative and knowledge issues, providing sufficient clear information and support to participants, and addressing concerns related to service providers and the regional center are crucial for improving participant engagement and retention in the program.

### ***Principles of Self-Determination***

In examining the remainder of the quantitative survey, item-level analysis is clustered by alignment with the principles of self-determination. For each question, differences by enrollment status in the SDP were explored to determine whether the program is furthering these principles and enhancing self-determination of enrolled participants. Statistical differences were observed on two items: In response to the question “I have enough help deciding how to use my individual budget/services,” 73% of SDP participants agreed that they had sufficient help in deciding how to use their individual budget and services in contrast to 54.3% of individuals who were not enrolled in the program, $\chi^2 = 7.60$, $p = .022$. This difference suggests that participation in the SDP may contribute to supported decision-making processes related to budget allocation and service utilization. Moreover, in response to the question, “My services and supports help me to have a good life,” 88.5% of current SDP participants expressed agreement that their services and supports contribute to a good life. A lower proportion of respondents who are not currently enrolled in the SDP (69.4%) agreed with the statement, $\chi^2 = 9.02$, $p = .011$. This finding highlights the positive impact of the SDP on participants’ perception of the effectiveness of their services and supports in facilitating a good life. See Table 2 for detailed item-level results by SDP enrollment.

> *““People with developmental disabilities and their families made it very clear that they really believe in the Self-Determination Program. There is faith and hope. They also want the program to be easier to use and fair for everyone. The State Council agrees, and we are committed to working towards that goal.”*
>
> *–Aaron Carruthers, Executive Director, SCDD*

> *“We were heartened to witness the overwhelming support for the Self-Determination Program. California’s investment in this program is leading to increased freedom, progress toward goals, and enhanced quality of life for people with intellectual and developmental disabilities. The results of the program evaluation point to critical ways to improve the Self-Determination Program, and the Tarjan Center is eager to support the systems involved in enhancing this important initiative.”*
>
> *– Dr. Liz Laugeson, Director, Tarjan Center at UCLA*

Table 2. Summary of Quantitative Survey Responses (as Percentages) and Group Comparisons by SDP Enrollment Status

| **Survey items** | **Response Option Categories** | **Full Sample** | **SDP Enrollment** | | **Sig.** |
|---|---|---|---|---|---|
| | | | Yes | No | |
| **FREEDOM [a]** | | | | | |
| **How pleased are you with where you live and who you live with?** | Pleased | 78.0 | 76.7 | 82.4 | *ns* |
| | Neutral | 7.7 | 6.8 | 11.8 | |
| | Unhappy | 14.3 | 16.4 | 5.9 | |
| **I can do things I enjoy as much as I like.** | Agree | 76.9 | 75.3 | 82.4 | *ns* |
| | Neutral | 12.1 | 15.1 | 0.0 | |
| | Disagree | 11.0 | 9.6 | 17.6 | |
| **I have friends that I like to talk to and spend time with.** | Agree | 68.9 | 68.1 | 70.6 | *ns* |
| | Neutral | 12.2 | 13.9 | 5.9 | |
| | Disagree | 18.9 | 18.1 | 23.5 | |
| **AUTHORITY** | | | | | |
| **How easy is it to understand the information about services and/or budget?** | Easy | 40.2 | 40.2 | 40.5 | *ns* |
| | Neutral | 18.8 | 18.6 | 16.2 | |
| | Difficult | 41.0 | 41.2 | 43.2 | |
| **How easy is it for you to make changes to your services and/or budget if you need to?** | Easy | 28.9 | 28.5 | 33.3 | *ns* |
| | Neutral | 19.7 | 18.5 | 22.2 | |
| | Difficult | 51.5 | 53.0 | 44.4 | |
| **SUPPORT** | | | | | |
| **Who makes decisions about how to use your support?** | Self and/or Others | 29.7 | 30.7 | 27.0 | *ns* |
| | Others | 70.3 | 69.3 | 73.0 | |
| **I have enough help deciding how to use my individual budget/services.** | Agree | 70.6 | **73.0** | **54.3** | ** |
| | Neutral | 12.2 | **10.0** | **25.7** | |
| | Disagree | 17.2 | 17.0 | 20.0 | |
| **I feel my service providers have the right training to meet my needs.** | Agree | 66.8 | 69.3 | 55.6 | *ns* |
| | Neutral | 17.6 | 16.1 | 25.0 | |
| | Disagree | 15.5 | 14.6 | 19.4 | |
| **RESPONSIBILITY** | | | | | |
| **How well do you understand your service plan?** | Very much understand | 34.2 | 35.4 | 27.8 | *ns* |
| | Somewhat understand | 51.1 | 51.5 | 47.2 | |
| | Do not understand at all | 14.8 | 13.1 | 25.0 | |
| **I have met my case manager/service coordinator.** | Yes | 84.1 | 84.0 | 83.3 | *ns* |
| | No | 15.9 | 16.0 | 16.7 | |
| **Do you currently have a paid job in the community? [b]** | Yes | 20.9 | 20.4 | 22.2 | *ns* |
| | No | 79.1 | 79.6 | 77.8 | |
| **CONFIRMATION** | | | | | |
| **What level of involvement did you have in making your Individual Program Plan?** | Involved | 89.4 | 90.4 | 82.4 | *ns* |
| | Not involved | 10.6 | 9.6 | 17.6 | |
| **My services and supports help me to have a good life.** | Agree | 85.8 | **88.5** | **69.4** | ** |
| | Neutral | 7.5 | 6.0 | 16.7 | |
| | Disagree | 6.7 | **5.5** | **13.9** | |
| **How in control do you feel about your Person-Centered Plan?** | High control | 48.7 | 50.3 | 38.9 | *ns* |
| | Moderate control | 27.3 | 27.1 | 30.6 | |
| | Low control | 23.9 | 22.6 | 30.6 | |

* *p* < .05, ** *p* < .01, *** *p* < .001. *ns* = not significant

a. Caregiver/parent respondents were excluded from the analysis of the three items within the Freedom section to ensure a more accurate representation of self-advocate perspectives and experiences. Notably, there were no significant group differences when caregiver/parent respondents were included in analysis.
b. Not applicable for 5 respondents, who were omitted from analysis.

To uncover potential disparities in experiences of enrolled SDP participants, demographic group comparisons by race and respondent type are reported in Table 3. Descriptive statistics for SDP participants on all items, as well as any significant differences by race, respondent type, age, gender, or diagnosis, are detailed below.

Table 3. Summary of Quantitative Survey Responses (as Percentages) and Group Comparisons by Respondent Type and Race among currently enrolled SDP Participants

| Survey items | Response Option Categories | Respondent | | Sig. | Race | | Sig. |
|---|---|---|---|---|---|---|---|
| | | Self | Caregiver | | BIPOC | White | |
| **FREEDOM** [a] | | | | | | | |
| **How pleased are you with where you live and who you live with?** | Pleased | -- | -- | -- | 79.5 | 77.8 | *ns* |
| | Neutral | -- | -- | | 9.1 | 6.7 | |
| | Unhappy | -- | -- | | 11.4 | 15.6 | |
| **I can do things I enjoy as much as I like.** | Agree | -- | -- | -- | 79.5 | 75.6 | *ns* |
| | Neutral | -- | -- | | 9.1 | 13.3 | |
| | Disagree | -- | -- | | 11.4 | 11.1 | |
| **I have friends that I like to talk to and spend time with.** | Agree | -- | -- | -- | 61.4 | 79.5 | *ns* |
| | Neutral | -- | -- | | 15.9 | 6.8 | |
| | Disagree | -- | -- | | 22.7 | 13.6 | |
| **AUTHORITY** | | | | | | | |
| **How easy is it to understand the information about services and/or budget?** | Easy | 38.9 | 41.3 | *ns* | 35.5 | 47.6 | *ns* |
| | Neutral | 15.3 | 21.1 | | 23.6 | 11.9 | |
| | Difficult | 45.8 | 37.6 | | 40.9 | 40.5 | |
| **How easy is it for you to make changes to your services and/or budget if you need to?** | Easy | 26.0 | 31.2 | *ns* | 29.1 | 28.2 | *ns* |
| | Neutral | 20.5 | 15.6 | | 16.4 | 22.4 | |
| | Difficult | 53.4 | 53.2 | | 54.5 | 49.4 | |
| **SUPPORT** | | | | | | | |
| **Who makes decisions about how to use your support?** | Self and/or Others | **55.6** | **15.6** | *** | 24.5 | 36.9 | *ns* |
| | Others | **44.4** | **84.4** | | 75.5 | 63.1 | |
| **I have enough help deciding how to use my individual budget/services.** | Agree | 75.3 | 73.4 | *ns* | 70.9 | 77.6 | *ns* |
| | Neutral | 9.6 | 9.2 | | 11.8 | 8.2 | |
| | Disagree | 15.1 | 17.4 | | 17.3 | 14.1 | |
| **I feel my service providers have the right training to meet my needs.** | Agree | 68.5 | 67.0 | *ns* | 64.2 | 77.6 | *ns* |
| | Neutral | 20.5 | 14.7 | | 19.3 | 11.8 | |
| | Disagree | 11.0 | 18.3 | | 16.5 | 10.6 | |

|  |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|---|
| **RESPONSIBILITY** |  |  |  |  |  |  |  |
| **How well do you understand your service plan?** | Very much understand | 45.8 | 29.6 | *ns* | 33.9 | 36.9 | *ns* |
|  | Somewhat understand | 45.8 | 54.6 |  | 50.9 | 53.6 |  |
|  | Do not understand at all | 8.3 | 15.7 |  | 15.9 | 9.5 |  |
| **I have met my case manager/service coordinator.** | Yes | 80.8 | 86.2 | *ns* | **79.1** | **90.6** | * |
|  | No | 19.2 | 13.8 |  | 20.9 | 9.4 |  |
| **Do you currently have a paid job in the community? [b]** | Yes | **32.9** | **14.0** | ** | 23.1 | 16.7 | *ns* |
|  | No | **67.1** | **86.0** |  | 76.9 | 83.3 |  |
| **CONFIRMATION** |  |  |  |  |  |  |  |
| **What level of involvement did you have in making your Individual Program Plan?** | Involved | 93.1 | 88.9 | *ns* | 88.9 | 91.8 | *ns* |
|  | Not Involved | 6.9 | 11.1 |  | 11.1 | 8.2 |  |
| **My services and supports help me to have a good life.** | Agree | 87.7 | 88.1 | *ns* | 85.5 | 92.9 | *ns* |
|  | Neutral | 5.5 | 6.4 |  | 10.0 | 1.2 |  |
|  | Disagree | 6.8 | 5.5 |  | 4.5 | 5.9 |  |
| **How in control do you feel about your Person-Centered Plan?** | High control | 50.7 | 48.1 | ** | **42.7** | **60.7** | ** |
|  | Moderate control | **17.8** | **34.3** |  | **36.4** | **15.5** |  |
|  | Low control | **31.5** | **17.6** |  | 20.9 | 23.8 |  |

*$p$ < .05, ** $p$ < .01, *** $p$ < .001. *ns* = not significant
a. Caregiver/parent respondents were excluded from the analysis of the three items within the Freedom section to ensure a more accurate representation of self-advocate perspectives and experiences. Notably, there were no significant group differences when caregiver/parent respondents were included in analysis.
b. Not applicable for 5 respondents, who were omitted from analysis.

**Freedom.** The self-determination principle of Freedom emphasizes the ability of individuals with disabilities, along with their freely chosen family and friends, to actively plan their own lives, with the necessary support. Three survey questions that focus on participants' perspectives related to their living situation and personal enjoyment tapped into the principle of Freedom. Caregiver/parent respondents were excluded from the analysis of the three items within this section to ensure a more accurate representation of self-advocate perspectives and experiences.

In response to the question, "How pleased are you with where you live and who you live with?", most participants (76.7%) reported feeling pleased with their living situation and the individuals they reside with. Conversely, 16.4% of participants expressed unhappiness, indicating dissatisfaction with their current living arrangements. SDP participants' satisfaction level with their living situation and cohabitants were consistent across demographic factors.

In response to the question, "I can do things I enjoy as much as I like," the findings indicate that 75.4% of the participants agreed to some extent, expressing their ability to engage in enjoyable activities as desired. On the other hand, 9.6% of participants disagreed, indicating limitations or restrictions in pursuing activities they enjoy. Age and gender emerged as factors that influenced SDP participants' responses. Specifically, participants under the age of 21 (63.9%) were less likely to agree than those aged 21 and over (83.2%), indicating a disparity in the perceived ability to engage in enjoyable activities based on age, $\chi^2 = 8.96$, $p = .011$. Furthermore, gender differences were evident, with 85.5% of females agreeing, compared to 71.1% of males, $\chi^2 = 6.67$, $p = .036$. This discrepancy suggests that females were more likely to perceive a greater level of freedom and opportunity to do things they enjoy. These findings underscore the importance of considering age and gender factors when addressing individuals' ability to pursue activities they enjoy while enrolled in the SDP.

In response to the statement, "I have friends that I like to talk to and spend time with," most respondents (68.1%) agreed, indicating a positive social connection. Conversely, a minority of respondents (18.1%) disagreed with the statement. No significant differences were found across examined demographic variables, highlighting the presence of friendships and social interactions among respondents.

**Authority**. In this section, responses to three survey questions related to the self-determination principle of Authority were examined. These questions explore the level of decision-making power and control that participants have in managing a budget to purchase services and supports of their choosing.

In response to the question, "How easy is it to understand the information about services and/or budget?", 40.2% of the respondents reported finding the information and services easy to understand to some extent, while 18.6% expressed a neutral stance. On the other hand, 41.2% of participants indicated that understanding the information and services was difficult to some extent. There were no statistically significant differences observed in group comparisons. These findings suggest that participants generally perceived varying levels of ease in comprehending the information and services offered within the program and highlights the importance of ongoing efforts to enhance clarity and accessibility.

In response to the question, "How easy is it for you to make changes to your services and/or budget if you need to?", 28.5% of the respondents reported finding it easy to make changes to their services and/or budget to some extent. 18.5% expressed a neutral stance, indicating neither ease nor difficulty in making changes. Conversely, 53% of participants indicated that it was difficult to some extent to make changes when necessary. There were no statistically significant differences observed in group comparisons. Inability to make changes with ease suggests that the current process may limit participants' authority to control their budget and services, emphasizing the need for continued efforts to improve the process for modifying services as needed.

**Support**. The support principle of self-determination emphasizes the significance of individuals with disabilities choosing the people and supports that enable them to live, work, and engage in their community. This principle recognizes the importance of personalized and tailored support systems that align with each individual's unique needs and aspirations. In this section, we examine three survey responses related to the principle of support, exploring participants' experiences and perspectives on selecting their support network and resources.

In response to the question, “Who makes decisions about how to use their support?”, 30.7% of all respondents reported that decisions were made by the SDP participant with or without a supportive other (e.g., parents, caregivers, or case managers). On the other hand, 69.3% reported that decisions were made solely by others. A notable difference was found among SDP participants based on respondent type and age. Specifically, 55.6% of self-respondents reported being involved in decision-making regarding the use of their supports, either independently or with others’ support, while only 15.6% of caregiver/parent respondents reported the self-advocate being involved. Conversely, 44.4% of self-respondents reported that other individuals made decisions about their use of supports without them, compared to 84.4% of caregiver/parent respondents endorsing this, $\chi^2 = 32.09$, $p < .001$. This suggests that there is a high level of uncertainty regarding autonomy and involvement in decision-making processes. It is also plausible that the parent respondent statistics were skewed due to children who were minors not being actively involved in decision-making. Indeed, age also showed a significant association, with 37.2% of respondents aged 21 and over reporting themselves with or without supportive others as decision-makers, while 20.8% of respondents representing individuals under the age of 21 reported self-advocate involvement, $\chi^2 = 5.51$, $p = .019$, which may be expected to some degree. There were no statistically significant differences observed in other group comparisons.

In relation to the statement, “I have enough help deciding how to use my individual budget/services,” 73.0% of the sample agreed with the statement. On the other hand, 17.0% disagreed, expressing a need for more assistance, while 10.0% remained neutral on the matter. There were no statistically significant differences observed in group comparisons, indicating that agreement with the statement was consistent across demographic factors among SDP participants.

Regarding the item, “I feel my service providers have the right training to meet my needs,” 69.3% of the full sample agreed, expressing confidence in the adequacy of their service providers’ training to address their needs. Conversely, 14.6% disagreed, indicating a lack of confidence in the training of their service providers. There were no statistically significant differences observed in group comparisons. These findings suggest that the perception of service providers’ training adequacy was consistent across diverse groups of SDP participants.

**Responsibility**. Responsibility is a fundamental principle of the SDP that emphasizes individuals’ ability to be accountable for decisions, particularly related to spending, taking charge of their lives, and being active in their community. In this section, we examine the responses to three survey items related to the principle of Responsibility. These items explore participants’ perceptions and experiences regarding their involvement in decision-making, their level of accountability for their IPP, and their understanding of their rights and responsibilities within the SDP.

In response to the question, “How well do you understand your service plan?”, 35.4% stated that they understood their service plan very well, 51.5% reported somewhat understanding, and 13.1% of respondents indicated that they did not understand their service plan at all. There were no statistically significant differences observed by demographic characteristics.

In response to the statement, “I have met my case manager or service coordinator,” most participants (84.0%) reported meeting with their case manager or service coordinator. Among SDP participants, a statistically significant difference was observed based on race, indicating that a lower percentage of BIPOC participants (79.1%) reported meeting their case manager or service coordinator compared to White participants (90.6%), $\chi^2 = 4.74$, $p = .029$. This finding speaks to the importance of addressing potential inequities in access to case managers or service coordinators based on race within the SDP. There were no statistically significant differences observed in other demographic comparisons.

In response to the question, “Do you have a paid job in the community?” most participants (79.6%) indicated that they do not have a paid job in the community. Among SDP participants, significant group differences were observed based on respondent type, with a higher percentage of self-respondents (32.9%) indicating that they have a paid job compared to caregivers/parents (14.0%), $\chi^2 = 9.09$, $p = .003$, which may also reflect parents representing a wide range of ages. Age was another significant factor among SDP participants, as a greater proportion of respondents aged 21 and over (26.8%) reported having a paid job in the community compared to those under the age of 21 (7.1%), $\chi^2 = 10.70$, $p = .001$, which is expected given the difference in employment opportunities and expectations for different age groups. There were no statistically significant differences observed in other demographic comparisons.

**Confirmation** – The self-determination principle of confirmation emphasizes the individual’s central role in making plans for their life and being involved in the creation of systems one interacts with. This principle is rooted in the core principle of self-determination, encapsulated by the phrase “nothing about you without you.” By analyzing responses to three specific survey questions in this section, we can gain insights into the extent to which participants feel validated, empowered, and involved in decision-making processes.

Most respondents (91.2%) reported having an Individual Program Plan (IPP) in place through the regional center, which serves as a comprehensive outline of their services and supports. Of these respondents, in reply to the survey item, “What level of involvement did you have in making your Individual Program Plan (IPP)?”, the results indicate that 90.4% of the participants reported being involved to some extent in the development of their IPP.

This finding suggests a high level of engagement and participation in decision-making regarding their IPP. Conversely, 9.6% of participants expressed not being involved in the development of their IPP. Among the SDP program participants, group comparisons revealed statistically significant differences based on age and diagnosis. Specifically, a greater proportion of respondents aged 21 and over (91.3%) reported involvement in their IPP compared to respondents under the age of 21 (81.8%), $\chi^2 = 12.36$, $p < .001$. This difference might be expected to some degree, considering the varying levels of independence and decision-making capacity that may arise with age. Regarding diagnosis, participants with autism alone exhibited a lower percentage (85.7%) of involvement in their IPP compared to participants with other diagnoses (95.6%), $\chi^2 = 5.36$, $p = .021$. This difference suggests that individuals with autism alone may face unique challenges or barriers to actively participating in the planning process of their IPP. There were no statistically significant differences observed in other group comparisons.

In response to the survey item, “My services and supports help me to have a good life,” 88.5% of respondents agreed to some extent that their services and supports contribute to a good life. Conversely, a smaller proportion of participants disagreed (5.5%), and 6.0% expressed a neutral stance. Group comparisons revealed a statistically significant difference across race. A greater proportion of BIPOC respondents (10.0%) reported being neutral compared to White respondents (1.2%), $\chi^2 = 6.54$, $p = .038$. Despite this difference, the overwhelming majority of both BIPOC and White respondents agreed with the statement, 85.5% and 92.9% respectively. There were no statistically significant differences observed in other group comparisons.

In response to the question, “How in control do you feel about your Person-Centered Plan (PCP)?”, 50.3% of participants reported a high level of control, indicating a strong sense of influence over their PCP. Additionally, 27.1% of participants indicated a moderate level of control, and 22.6% reported a low level of control. Significant group differences were observed within SDP participants based on respondent type and race. When comparing respondents’ levels of control, self-respondents indicated lower levels of control compared to caregivers/parents. Specifically, 31.5% of self-respondents reported a low level of control, whereas only 17.6% of caregivers/parents expressed the same, and 17.4% of self-respondents reported a moderate level of control compared to 34.3% of caregivers/parents, $\chi^2 = 7.96$, $p = .019$. Regarding racial differences, BIPOC respondents indicated lower levels of control compared to White respondents. A larger proportion of BIPOC individuals indicated having a moderate level of control (36.4%) compared to White participants (15.5%), and a smaller proportion of BIPOC respondents indicated having a high level of control (42.7%) compared to White participants (60.7%), $\chi^2 = 10.84$, $p = .004$. By understanding the levels of control experienced by participants in relation to their PCP, efforts can be made to enhance the self-determination and empowerment of individuals with disabilities.

## Virtual Focus Groups

### *Emergent Themes*

Results from the nine focus groups with different stakeholders revealed a variety of emergent themes. These themes can be grouped into those related to helpful components and positive outcomes (Figure 3), as well as barriers and challenges (Figure 4), in the SDP.

Figure 3. *Emergent Themes of Helpful Components and Positive Outcomes in the Self-Determination Program from Virtual Focus Groups*

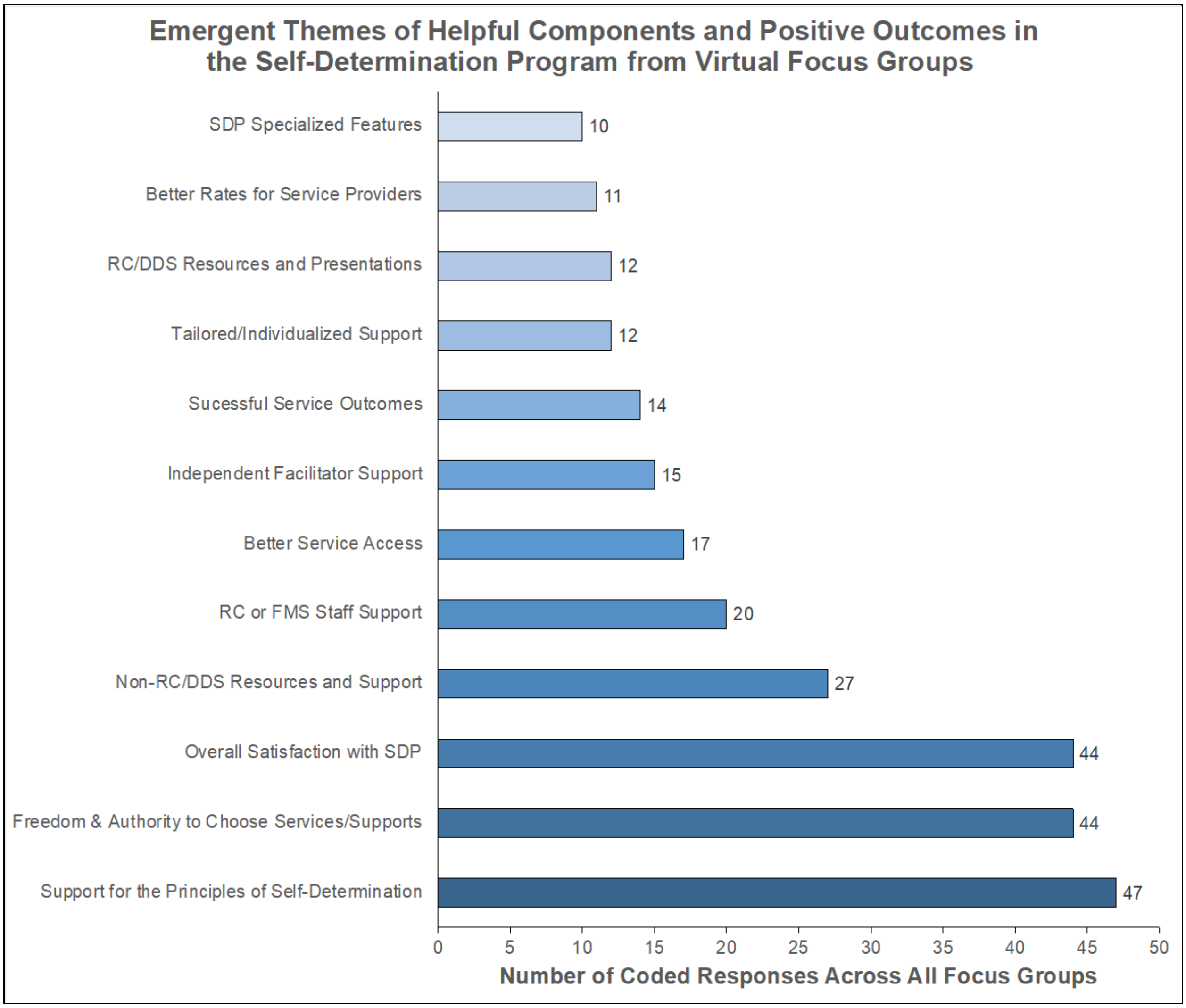
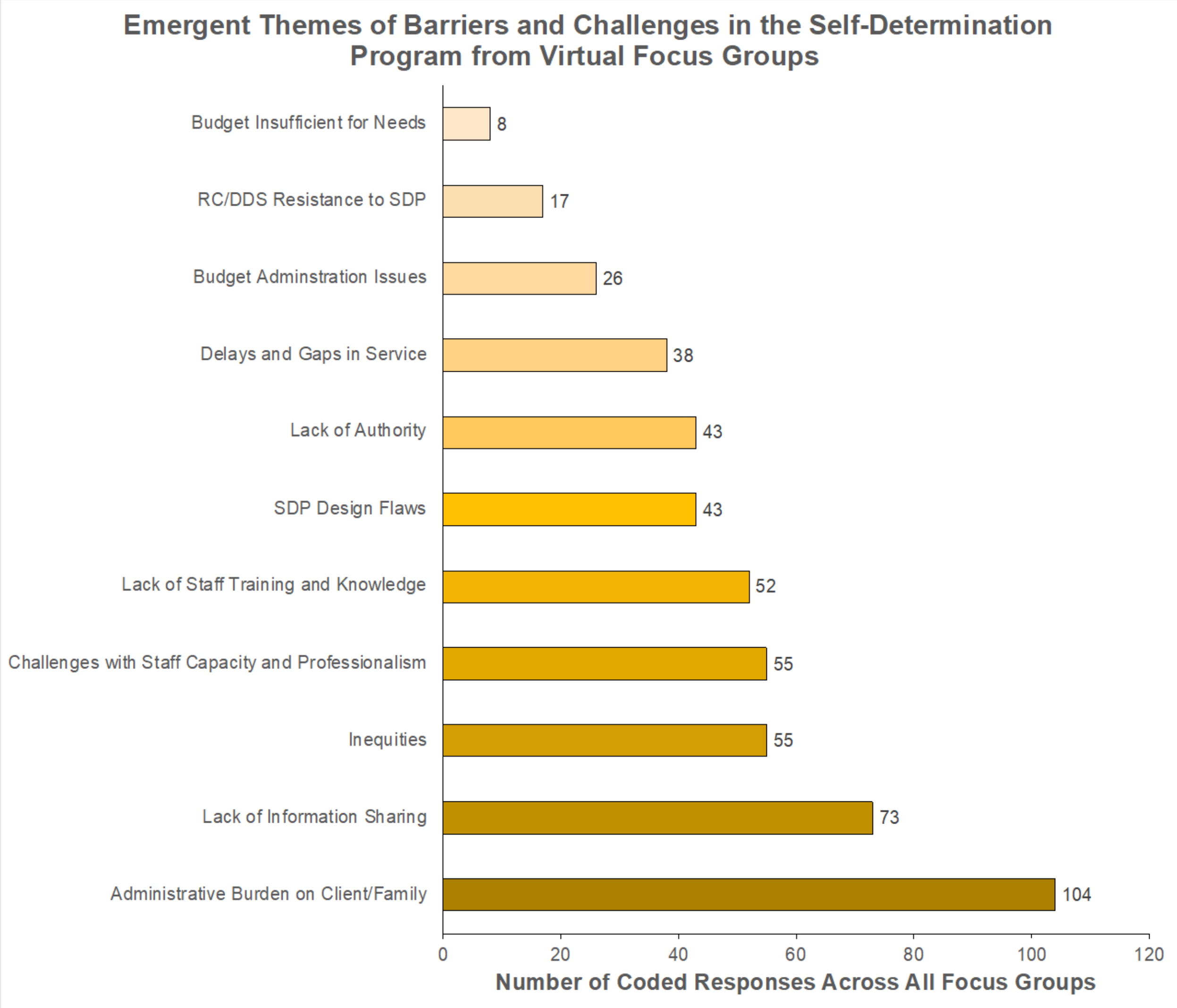


Figure 4. *Emergent Themes of Barriers and Challenges in the Self-Determination Program from Virtual Focus Groups*



**Helpful Components and Positive Outcomes in the Self-Determination Program.** The most frequent theme was the *Support of the Principles of Self-Determination* (46 coded responses), with several people sharing their belief in the rights to freedom, authority, support, responsibility, and confirmation for all. A regional center client beginning the SDP enrollment process described self-determination as a "a revolutionary idea that people with disabilities are in charge of their own lives." Others expressed their support by agreeing with the broad intentions of the SDP and sharing that it has great promise and potential. A parent was passionate about the concept, saying that it creates space for families to "start seeing beyond 'this is just my need'… they can start thinking about what are [the client's] interests and dreams and let's talk about funding those things, which is really amazing." An independent facilitator shared "the best thing is the hope and excitement people feel when they hear about the concept… a lot of the people that I've helped have a renewed sense of hope."

Within the SDP itself, focus group participants reported how the program enhanced their *Freedom and Authority to Choose Services/Supports* (45 coded responses). A parent of an enrolled participant reported being able to “choose and do so much more. I was able to do camp, respite, and services like tutoring and buying hard things like a computer.” Other parents described using their budgets toward microenterprises, business classes, college supports, adaptive skills, swimming lessons, music lessons, personal trainers, personal assistants, and mental health services. One regional center client in the program shared that “the Self-Determination Program has been helpful by making me be resourceful and having control over my spending.” They shared that this sense of making “certain decisions alone [with a] sense of freedom and sense of responsibility has been really helpful in the Self-Determination Program.” Parents whose loved ones were not yet enrolled also anticipated this benefit, with parents expecting to being able to “access services for my son that are not traditional or hard to find on the vendor list” and to “utilize the funding for services that are more meaningful for my family.”

Patterns in other more specific impacts of the SDP on service access and provision were also noted, including *Better Service Access* (17 coded responses), receiving *Tailored/Individualized Support* (12 coded responses), and being able to pay *Better Rates for Service Providers* (11 coded responses). In general, focus group participants described the program as expanding their options for service providers, allowing them “to be able to find service providers quickly and… within our own community” that “match well” with the needs of the person with a disability. Some focus group participants specifically referenced increased and more equitable service access in rural and diverse communities. Being able to pay service providers better rates was also noted as a significant benefit, leading to the ability to access highly specialized providers and creating more consistent, long-term support with less turnover. In turn, participants and families observed *Successful Outcomes* (14 coded responses), including progress toward goals (e.g., academic, employment), improved mental health, enhanced independence/responsibility, and increased quality of life. One parent summarized: “SDP is more comparable to a custom solution, as opposed to a standard one size fits all approach. With SDP we were able to support our son where he was at with his needs and move forward with higher and better-quality outcomes.”

Following from these impacts on service provision was another common positive theme: *Overall Satisfaction with the Self-Determination Program* (44 coded responses). Indeed, six different focus group participants described the program as “life-changing.” One parent shared, “the overall experience has literally been life changing for our son, who is 16 years old. It’s really an amazing program because it provides flexibility and gives us the ability to focus on him as an individual… we are very happy with the outcome and I think based on his experience and what he has communicated to us, he’s also very pleased with the program.” Several attendees were also clear to express that although there have been challenges and they hope the program can improve, they are grateful for this option and believe the program has been worth it or was the right choice for them.

Regional center clients, their families, and independent facilitators (IFs) shared resources that have been helpful in learning about the Self-Determination Program and while enrolled in the program. The most common sources of support were external to the regional center (RC) and DDS, taking the form of other families, social media groups, friends, and non-profit resources, such as SDP Connect (*Non-RC/DDS Resources and Support*, 27 coded responses). Within the SDP system, some families were grateful for the support of their service coordinator, the participant choice specialists, ombudspersons, Financial Management Services (FMS) staff, and the Self-Determination Advisory Committee (*RC or FMS Staff Support*, 20 coded responses). Many also found *Independent Facilitator Support* (15 coded responses) to be helpful, calling it a “game-changer” and “super supportive to everyone involved.” Stakeholders also found information and trainings hosted by regional center and DDS to be helpful, including the initial orientation, flyers, emails, and conferences (*RC/DDS Resources and Presentations*, 12 coded responses).

Finally, some *SDP Specialized Features* (10 coded responses) were highlighted through the focus group conversations, including finding the person-centered plan and individualized spending plan helpful.

**Barriers and Challenges.** Despite the many positives that emerged from the focus groups about the SDP, there were also barriers and challenges identified. The most common of these, with over 100 coded responses and accounting for 20% of all negative valence codes, was the amount of *Administrative Burden on the Client and Family* produced by the SDP. A self-advocate reported “I get no support from the regional center. I get to figure out everything myself as this whole process seems a bit confusing to me,” while another suggested that the “service coordinator should help you find your IF and FMS because to just leave that on the prospective SDP client, all by themselves, I mean that’s a bit overwhelming.” Parents echoed these sentiments, saying “I felt on my own a lot,” and “I had to do everything by myself.” Families shared having gone to extraordinary lengths to access the program, including doing extensive research on their own, including taking time off work, retiring, and completing the independent facilitator training to learn about the program for their child. One adult credited his family for getting him in to the SDP. Beyond the enrollment and ongoing administrative needs, families also felt unsupported in locating service providers once unrestricted by the vendor system. Several recommendations were made to create a “clearinghouse of resources all up and down the state where you go to a website, you click which county you are in, and [what service type]… [because] it just seems like the burden is really on [families] to find all these resources.” Parents whose children were not currently enrolled also cited these burdens as a barrier, saying that the program seems “very confusing, very labor intensive…complicated and complex.” One parent was unsure the program was worth the challenges, “while it’s nice to believe that self-determination would give us this freedom, it once again dumps everything on us to try to figure it out… parents like me tend to hesitate and wonder how is this really going to help us because then I would need to deal with a whole other pile of paperwork.”

Families also felt there was a *Lack of Information Sharing* (73 coded responses) and transparency about the SDP. Sentiments about information sharing largely fell into three categories: 1) desire for increased awareness about the program, 2) easier access to information about how to navigate the program, and 3) more detailed explanations by regional center about decisions, particularly about budgets and rates. Regional center clients felt that "advertisements should be made so people are aware because people are not so aware about SDP," and complained that they "couldn't find adequate information on how to enroll in the program." Parents echoed a desire for more outreach, especially to historically underserved communities. Both parents and self-advocates felt that their service coordinator should have brought up the SDP as an option but did not. Many people suggested visual supports, such as checklists, a "road map," or having "step by step what happens next in plain language."

*Inequities* (55 coded responses) was another challenge identified within the SDP. Our focus group participants were keenly aware of how the culmination of both burden and lack of information could also contribute to inequities, sharing how families with less flexible work schedules or for whom English was a second language would struggle to navigate the program. Multiple regional center clients and their families shared experiencing stigma and discrimination at some point in their experience with SDP. Another repeated example of inequity noted by focus group participants was the lack of plain language in orientation and other materials. One parent shared that her son attended the training with her but was "very frustrated with all of the acronyms that were used, all of the language that was used… it was not accessible to him." Notably, in the focus group with independent facilitators who have knowledge across multiple clients, inequities across regional centers were the most concerning. Per their experience, "the disparity between the regional centers in how they enact the program is a huge challenge. The easy to work with regional centers have found ways to make the program work with the supports and services participant want, while other regional centers interpret the program and its rules strictly so that very few of the creative services are permitted." They also see this inequity in budgets: "individuals experience vastly different budgets depending on which regional center or service coordinator team I'm working with. These budget differences for similar client needs are on the order of tens of thousands of dollars." Inequity across regional centers was the most commonly coded form of inequity across the nine focus groups.

Challenges with SDP staff also emerged, spanning across regional center staff, FMS staff, and IFs. *Challenges with Staff Capacity and Professionalism* was a frequently expressed sentiment (54 coded responses). The most common complaints within this theme surrounded FMS agencies, which were split between concerns about long waitlists for FMS services and receiving poor customer service from FMS staff (e.g., not responding to emails, needing to follow up multiple times). Following FMS, regional center staff capacity concerns were also frequent, most often citing service coordinator turnover. Comments about IFs highlighted the lack of availability of knowledgeable IFs.

Many stakeholders also expressed frustration with the *Lack of Staff Knowledge and Training* (52 coded responses) in the SDP process. Parents described many "challenges dealing with FMS's and service coordinators who don't understand the program," where "each [new service coordinator] doesn't know much about SDP… I feel like I'm always educating." Those families who haven't enrolled yet cited this lack of knowledge as one contributing factor: "the biggest obstacle for me was the knowledge of my service coordinator… it was almost like she had no idea what to do and a lot of the things that she said to me didn't match up with the what I was reading from the resources… it's been a couple years that we've been trying to work through it." Although a few participants mentioned lack of knowledge of FMS staff, the vast majority of concerns about staff knowledge were directed toward regional center service coordinators. Though less common, there were 17 coded responses of *Systemic Resistance to SDP*, where stakeholders felt as though the "attitudes and culture of the regional center [are] traditional, traditional, traditional [services]." One regional center client said that when they "initially did it with my service coordinator, he basically tried to get me out of the idea of going into SDP, but I persisted, so he finally initiated it." An independent facilitator expressed that the "regional center would prefer us not to [create life goals] because we are creating needs for more services when we come up with really positive goals."

Clients and their families reported experiencing a *Lack of Authority* (43 coded responses). Regional center clients themselves often experienced a lack of authority in the decision-making process and expressed a desire for their voice to be prioritized: "for me it should just be about the person and worker… at times family members might make it hard on you that you don't even be able to make decision and choices, you don't have no choice." A woman in her 30's reported: "I'm an independent living adult, they keep contacting my mom… they invited her to my IPP meeting and not me. I don't get included in the emails, but she does." In contrast, lack of authority as reported by parents was more often experienced through desired services being denied, wanting more flexibility and freedom in how to spend one's budget, or a desire to be able to advocate on committees in the SDP process.

Although less common, *Budget Administration Issues* (26 coded responses) and feeling as though the *Budget is Insufficient* given client needs (8 coded responses) also were endorsed by the focus group participants. Administration issues encompassed a variety of difficulties with the Financial Management Systems, including slow payment, accounting errors, slow updating of accounting, and inability to easily track spending (e.g., through an online system). Some families also felt that the budgets did not reflect the marketplace of service providers and associated rates. These both led to delays or gaps in services at times, as families felt they could only afford four to six months of a service instead of 12, given the rates in the community, while slow payment from the FMS interfered with employee retention and paperwork delays led to clients losing "spots" in limited availability services, like camps. When able, families reported paying out of pocket to prevent these gaps in services while waiting for the FMS payment.

Often in connection to other barriers, significant *Delays and Gaps in Services* (38 coded responses) also emerged as a common theme. One parent shared, “we’re not enrolled yet, we’re in line to get things in line… one obstacle is there’s a waiting list for everything…last time I spoke to my service coordinator she told me it could be more than a year.” Eight focus group participants reported having waited, or continuing to wait, over a year to fully enroll and get started in the program. Once in the program, families continued to describe delays and gaps, as described above.

Finally, stakeholders shared their perspectives on flaws in the design of the Self-Determination Program (*SDP Design Flaws*, 43 coded responses). Recurrent flaws expressed by multiple stakeholders included: having to pay for an independent facilitator out of another budget line item (rather than being a separate line item, like the FMS), needing to renew budgets annually, lack of strict deadlines for each step of the enrollment process, the low reimbursement rates for FMS’s (which is exacerbating the shortage of FMS capacity), frequently changing policies, and the lack of oversight, evaluation, and accountability. One regional center client also felt that the FMS requirements for businesses to complete certain documents violated their privacy, since “anytime I have someone fill out these forms, it tells them I am a regional center client.”

### *Themes Across Different Participant Types*

Representation of themes across different participant types (i.e., enrolled SDP participants, caregivers of enrolled SDP participants, regional center clients not currently enrolled in SDP, caregivers of regional center clients not currently enrolled in SDP, and independent facilitators) was broadly similar, with a few notable exceptions. Among positive themes (see Table 4), participants, caregivers, and independent facilitators currently affiliated with the SDP were more likely to have been coded for themes of *Overall Satisfaction with the SDP* and *Successful Outcomes*. In contrast, participants and caregivers who were not currently affiliated with the program more frequently endorsed *Support for the Principles of Self-Determination*, likely due to their lack of direct experience with the program. Among barriers and challenges (see Table 5), those not currently enrolled in the program had the highest proportions of codes associated with *Lack of Information Sharing*. As those not informed of or provided with information about the program would be more highly represented in the non-enrolled group, this is a logical relationship. On the other hand, those who were enrolled in the SDP program were more frequently impacted by *Challenges with Staff Capacity and Professionalism* than those not currently enrolled.

Table 4. Frequency of Themes Representing Helpful Components and Positive Outcomes in the Self-Determination Program by Participant Type in Virtual Focus Groups

| Helpful Components and Positive Outcomes | SDP Participants | Caregivers of SDP Participants | RC Clients Not Enrolled in SDP | Caregivers of RC Clients Not Enrolled in SDP | Independent Facilitators |
|---|---|---|---|---|---|
| Support for the Principles of Self-Determination | 4 (10%) | 4 (5.2%) | 16 (38.8%) | 21 (36.2%) | 2 (3.6%) |
| Freedom and Authority to Choose Services & Supports | 7 (17.5%) | 11 (14.3%) | 7 (16.7%) | 6 (10.3%) | 13 (23.2%) |
| Overall Satisfaction with SDP | 8 (20%) | 19 (24.7%) | 3 (7.1%) | 1 (1.7%) | 13 (23.2%) |
| Non-RC/DDS Resources/Support | 3 (7.5%) | 8 (10.4%) | 6 (14.3%) | 9 (15.5%) | 1 (1.8%) |
| RC or FMS Staff Support | 3 (7.5%) | 7 (9.1%) | 2 (4.8%) | 5 (8.6%) | 3 (5.4%) |
| Better Service Access | 1 (2.5%) | 5 (6.5%) | 1 (2.4%) | 4 (6.9%) | 6 (10.7%) |
| Independent Facilitator Support | 3 (7.5%) | 4 (5.2%) | 1 (2.4%) | 0 (0%) | 7 (12.5%) |
| Successful Outcomes | 8 (20%) | 4 (5.2%) | 0 (0%) | 0 (0%) | 2 (3.6%) |
| Tailored/Individualized Support | 1 (2.5%) | 6 (7.8%) | 1 (2.4%) | 1 (1.7%) | 3 (5.4%) |
| RC/DDS Resources/Presentations | 0 (0%) | 4 (5.2%) | 0 (0%) | 8 (13.8%) | 0 (0%) |
| Better Rates for Service Providers | 1 (2.5%) | 3 (3.9%) | 2 (4.8%) | 2 (3.4%) | 3 (5.4%) |
| SDP Specialized Features | 1 (2.5%) | 2 (2.6%) | 3 (7.1%) | 1 (1.7%) | 3 (5.4%) |

Table 5. Frequency of Themes Representing Barriers and Challenges in the Self-Determination Program by Participant Type in Virtual Focus Groups

| **Barriers and Challenges** | **SDP Participants** | **Caregivers of SDP Participants** | **RC Clients Not Enrolled in SDP** | **Caregivers of RC Clients Not Enrolled in SDP** | **Independent Facilitators** |
|---|---|---|---|---|---|
| Administrative Burden on Client and Family | 12 (18.8%) | 36 (20.9%) | 9 (15.8%) | 33 (25.4%) | 14 (15.4%) |
| Lack of Information Sharing | 2 (3.1%) | 16 (9.3%) | 20 (35.1%) | 27 (20.8%) | 8 (8.8%) |
| Inequities | 6 (9.4%) | 16 (9.3%) | 11 (19.3%) | 9 (6.9%) | 13 (14.3%) |
| Challenges with Staff Capacity and Professionalism | 9 (14.1%) | 22 (12.8%) | 2 (3.5%) | 10 (7.7%) | 12 (13.2%) |
| Lack of Staff Knowledge/Training in SDP | 10 (15.6%) | 22 (12.8%) | 4 (7%) | 12 (9.2%) | 4 (4.4%) |
| SDP Design Flaws | 7 (10.9%) | 14 (8.1%) | 2 (3.5%) | 9 (6.9%) | 11 (12.1%) |
| Lack of Authority | 8 (12.5%) | 10 (5.8%) | 5 (8.8%) | 8 (6.2%) | 12 (13.2%) |
| Delays and Gaps in Services | 6 (9.4%) | 13 (7.6%) | 0 (0%) | 12 (9.2%) | 7 (7.7%) |
| Budget Administration Issues | 2 (3.1%) | 14 (8.1%) | 0 (0%) | 3 (2.3%) | 7 (7.7%) |
| RC/DDS Resistance to Self-Determination | 1 (1.6%) | 8 (4.7%) | 2 (3.5%) | 4 (3.1%) | 2 (2.2%) |
| Budget Insufficient for Needs | 1 (1.6%) | 1 (0.6%) | 2 (3.5%) | 3 (2.3%) | 1 (1.1%) |

### ***Connection to the Principles of Self-Determination***

Though qualitative coding using inductive methods allows for themes to emerge from the data without imposing a predetermined structure, the themes expressed by participants, family members, and independent facilitators align with the principles of self-determination in many ways. Participants' high degree of *Support for the Principles of Self-Determination* is representative of the principle of confirmation, where individuals with disabilities are involved in making decisions regarding the design and operation of the systems with which they interact. Participants' clear support for the concept of the SDP suggest their commitment to sharing their voice to shape and maintain this program to achieve its potential. This was further echoed in the code *SDP Design Flaws* and *Lack of Authority*, where several participants shared a desire to advocate and give feedback on committees and in the ongoing evaluation of the program, as well as in *Systemic Resistance to Self-Determination*, where participants were highlighting problems in the current systems that serve them.

Focus group participants also heavily emphasized that the SDP allowed them *Freedom & Authority to Choose Services and Supports*. Individuals and families greatly appreciated the ability in the SDP to design their own spending plans, identify both traditional and creative types of services, and choose their service providers. Though this theme touches on elements of the principles of authority and support, it truly encompasses the full rights of freedom for people with developmental disabilities to choose and pursue life goals and supports, just as people without developmental disabilities do. The theme of *Better Service Access* also encapsulates freedom of choice, with stakeholders no longer being limited to specific vendors in the traditional service system. Within this theme, families expressed being free to prioritize and arrange support services faster (by being able to choose agencies without long waitlists), which were closer to their home, and with providers who would come to the home or go out in the community with the participant. Ultimately, many of the examples of *Successful Outcomes* highlight how the SDP has enabled participants to have a higher quality of life and to live a life of their choosing, whether that includes operating a jewelry microenterprise, moving into an apartment, or getting supports to quit smoking. Successes also highlighted enhanced responsibility, including self-discipline and intentionality when planning services and allocating budgets, as well as improved community integration for people of all ages. Interestingly, many participants simultaneously highlighted advancements in their freedom and authority provided by the SDP, while also sharing ways in which these principles are still limited, for example, when desired services are denied (*Lack of Authority*). The frequent combination of these codes suggests that California's SDP did indeed lead to large gains in Freedom for people with developmental disabilities, though there continues to be room for improvement.

The barriers and challenges that emerged from the focus groups also highlight areas where the SDP can improve and continue to make movement toward individuals with developmental disabilities achieving self-determination. Four of the five most frequently coded themes all align with the principle of support: *Burden on Client and Family, Lack of*

*Information. Sharing, Challenges with Staff Capacity and Professionalism, and Lack of Staff Training and Knowledge*. Though distinct themes, the consistency among them strongly emphasizes the need for improved access to effective supports that enable individuals with developmental disabilities to live a full life. This includes information about program options and formal supports from professionals involved in the administration of the SDP that reduce the weight on families.

## Qualitative Survey

***Emergent Themes***

In general, thematic frequency in the qualitative survey followed a similar pattern as in the virtual focus groups, reinforcing the validity of these elements. With respect to helpful components and positive elements, the top three most frequently endorsed ideas remained the same in the qualitative survey as in the virtual focus groups (*Freedom and Authority to Choose Services/Supports:* 24% of qualitative survey positive codes*, Support for the Principles of Self-Determination:* 15%, *Overall Satisfaction with SDP:* 14%). Though the top two barriers and challenges (*Burden on Client and Family, Lack of Information Sharing*) remained the same across program evaluation phases, respondents to the qualitative survey identified more *SDP Design Flaws*, with this as the third most commonly applied code. In addition to the design flaws identified and discussed in the live virtual focus group results above, repeated design flaws that were reported in the qualitative survey included challenges with FMS payment policies used by families to access services (e.g., wanting to have a credit card or gift card to be able to pay for a service in advance and/or pay service providers who are not a FMS vendor), standardization and accessibility of paperwork, and problems with the provider enrollment process and regulations acting as a deterrent for providers (e.g., Livescan and Motor Vehicle Record process, not allowing providers to be employed by more than one SDP participant).

Table 6. Frequency of Themes Representing Helpful Components and Positive Outcomes in the Self-Determination Program within the Qualitative Survey and Virtual Focus Groups

| Helpful Components and Positive Outcomes | Written Qualitative Survey | Virtual Focus Groups | Total Thematic Frequency |
|---|---|---|---|
| Freedom and Authority to Choose Services & Supports | 166 (24%) | 44 (16%) | 210 (21%) |
| Support for Principles of SDP | 105 (15%) | 47 (17%) | 152 (16%) |
| Overall Satisfaction with SDP | 97 (14%) | 44 (16%) | 141 (14%) |
| Unspecified Support | 77 (11%) | | 77 (8%) |
| Successful Outcomes | 54 (8%) | 14 (5%) | 68 7%) |
| Better Service Access | 34 (5%) | 17 (6%) | 51 (5%) |
| Independent Facilitator Support | 31 (4%) | 15 (6%) | 46 (5%) |
| Tailored Individualized Support | 31 (4%) | 12 (5%) | 43 (4%) |
| SDP Specialized Features | 30 (4%) | 10 (4%) | 40 (4%) |
| Non-RC Supports/Resources | 23 (3%) | 27 (10%) | 50 (5%) |
| RC or FMS Staff Support | 23 (3%) | 20 (7%) | 43 (4%) |
| Better Rates for Providers | 21 (3%) | 11 (4%) | 32 (3%) |
| RC/DDS Resources/Presentations | 14 (2%) | 12 (4%) | 26 3%) |

Table 7. Frequency of Themes Representing Barriers and Challenges in the Self-Determination Program within the Qualitative Survey and Virtual Focus Groups

| **Barriers and Challenges** | **Written Qualitative Survey** | **Virtual Focus Groups** | **Total Thematic Frequency** |
|---|---|---|---|
| Burden on Client and Family | 139 (17%) | 104 (20%) | 243 (18%) |
| Lack of Information Sharing | 111 (14%) | 73 (14%) | 184 (14%) |
| SDP Design Flaws | 92 (11%) | 43 (8%) | 135 (10%) |
| Challenges with Staff Capacity & Professionalism | 88 (11%) | 54 (11%) | 143 (11%) |
| Financial Management Service | 43 | 23 | 66 |
| Regional Center | 22 | 16 | 38 |
| Independent Facilitators | 14 | 8 | 22 |
| Lack of Authority | 84 (10%) | 43 (8%) | 127 (9%) |
| Inequities | 64 (8%) | 55 (11%) | 119 (9%) |
| Native Language | 12 | 2 | 14 |
| Disability | 12 | 4 | 16 |
| Racial | 11 | 8 | 19 |
| Regional Center | 7 | 12 | 19 |
| Socioeconomic/Education | 5 | 9 | 14 |
| Urbanicity | 2 | 3 | 5 |
| Budget Administration Issues | 44 (5%) | 26 (5%) | 70 (5%) |
| Delays and Gaps in Service | 40 (5%) | 38 (8%) | 78 (6%) |
| Lack of Staff Training and Knowledge in SDP | 35 (4%) | 52 (10%) | 87 (6%) |
| Personal Barriers | 32 (4%) | | 32 (2%) |
| Unspecified Difficulty Enrolling | 27 (3%) | | 27 (2%) |
| Systemic Resistance to Self-Determination | 23 (3%) | 17 (3%) | 40 (3%) |
| Unspecified Financial Barrier | 18 (2%) | | 18 (1%) |
| Budget Insufficient for Needs | 15 (2%) | 8 (2%) | 23 (2%) |
| Unspecified Obstacles | 6 (1%) | | 6 (0.5%) |

Given that some responses in the written survey were short and less detailed, new codes were added to represent *Unspecified Support* as a helpful component, which was coded when participants generally reported having support in the process of enrolling and navigating the Self-Determination Program but did not specify what kinds of support were provided or by whom. Similar codes were added to barriers and challenges, representing *Unspecified Obstacles*, *Unspecified Financial Barriers*, and *Unspecified Difficulty Enrolling* (i.e., participants reported difficulty enrolling in SDP, but did not specify the barriers). One new code, *Personal Barriers,* was added based on emergent themes to capture survey respondents who reported a lack of self-awareness, mental health challenges, and/or impulsivity interfering with their experience in the Self-Determination Program. Such challenges were not discussed in the live virtual focus groups. In Tables 6 and 7, thematic frequency in the qualitative survey, virtual focus groups, and in sum across both methodologies is presented for Helpful Components and Positive Outcomes as well as Barriers and Challenges, respectively.

### *Group Differences*

On average, respondents to the qualitative survey were coded for 5.7 ($SD = 4.3$) themes per response, which could include two instances of a singular theme if the content were distinct ideas. Respondents were coded for a similar number of positive ($M = 2.7$, $SD = 2.0$) and negative themes ($M = 3.1$, $SD = 3.0$) per response. Enrolled participants and family members (referred to in aggregate as "stakeholders" moving forward) were significantly more lengthy, $t(252) = -2.67$, $p = .011$, and had a greater number of positive codes in their responses, $t(253) = -4.19$, $p < .001$, as compared to stakeholders who were not currently enrolled. This may be expected due to a richer experience with the SDP. Further, family members of current participants were more lengthy in their responses than currently enrolled participants reporting for themselves, $t(156) = 3.51$, $p < .001$. Family members of enrolled participants also were coded for a greater number of negative valence codes ($M = 3.9$, $SD = 3.4$) than enrolled participants themselves ($M = 2.2$, $SD = 2.5$), $t(156) = -3.55$, $p < .001$. This is consistent with the high thematic salience of *Burden on Client and Family* and lack of support received by family members.

**Differences in Emergent Themes by Enrollment in SDP.** To examine whether stakeholders reported different positive experiences or barriers depending on their current SDP enrollment status, Chi-squared tests comparing binary presence/absence of themes by enrollment status were conducted, excluding independent facilitators. With respect to barriers and challenges, stakeholders who were not enrolled were significantly more likely to report an *Unspecified Difficulty Enrolling*, $\chi^2 = 10.50$, $p = .001$, with 19% of non-enrolled stakeholders being coded for this theme as compared to 6% for enrolled stakeholders. Additionally, there was a statistically significant difference in the likelihood that stakeholders expressed a *Lack of Information Sharing*, $\chi^2 = 15.00$, $p < .001$. Specifically, while 27% of enrolled stakeholders highlighted this challenge, 51% of those who were not currently enrolled felt they did not receive sufficient information about the SDP. These disparities in access to information about the program are likely linked to difficulties enrolling. In contrast, enrolled stakeholders were significantly more likely to report on *SDP Design Flaws* (27%) than stakeholders not currently enrolled in the program (15%), $\chi^2 = 4.28$, $p = .039$. Enrolled stakeholders also were more likely than those who were not enrolled to report *Personal Barriers*, $\chi^2 = 15.69$, $p < .001$, and *Unspecified Financial Barriers*, $\chi^2 = 8.67$, $p = .003$, in SDP. No other significant differences emerged by enrollment status in endorsement of barriers and challenges.

Turning to helpful components and positive outcomes, stakeholders who were not enrolled in the program were more likely to be coded for *Support for the Principles of Self-Determination* (67%) than enrolled stakeholders (21%), $\chi^2 = 54.04$, $p < .001$. In contrast, enrolled stakeholders were significantly more likely to endorse *Freedom and Authority to Choose Services & Supports* as a benefit of SDP (63%), $\chi^2 = 13.33$, $p < .001$, and feelings of *Overall Satisfaction with SDP* (49%), $\chi^2 = 48.05$, $p < .001$. Many other positive outcomes were significantly or marginally more likely to be endorsed by those currently enrolled in the program, including: *Successful Outcomes*, $\chi^2 = 7.12$, $p = .008$, *Better Rates for Providers*, $\chi^2 = 4.72$, $p = .030$, *Independent Facilitator Support*, $\chi^2 = 10.65$, $p = .001$, *SDP Specialized Features*, $\chi^2 = 6.30$, $p = .012$, and *Better Service Access*, $\chi^2 = 3.12$, $p = .077$. These findings underscore that once in the program, many benefits are experienced by participants and families. No significant differences by enrollment status were observed in the remaining positive codes, most of which centered on sources of support and information.

### Demographic Differences in Emergent Themes within SDP participants.

***Race.*** Next, we aimed to explore whether different groups of participants in the SDP had different perspectives on or experiences with the program while enrolled. In examining racial differences, BIPOC stakeholders in the SDP were significantly less likely to report having received *Support from Regional Center Staff* (4%; e.g., service coordinator, advisory committees, ombudsperson) than White stakeholders (17%), $\chi^2 = 6.85$, $p = .009$. Though on a trend level, the data also suggested that BIPOC stakeholders observed more *Successful Outcomes*, $\chi^2 = 3.57$, $p = .059$, with 26% of BIPOC stakeholders having expressed this sentiment in their written response, in contrast to only 14% of White stakeholders. This result is encouraging, suggesting that historically underserved populations may be seeing positive results and progress from the SDP. No other significant differences in thematic presence by race emerged in the qualitative responses.

***Age.*** With respect to age, stakeholders associated with younger SDP clients (0-17 years old) were significantly more likely than younger adults (18-30 years old) and older adults (31 years old and up) to report *Systemic Resistance to Self-Determination* from the Regional Center, $\chi^2 = 7.43$, $p = .024$. Twenty-one percent of respondents reported this experience, likely parents of minors, as compared to 3-5% of adults. Similarly, stakeholders associated with younger clients of the SDP were also more likely to report *Challenges with SDP Staff Capacity and Professionalism*, $\chi^2 = 8.08$, $p = .018$, at a rate of almost half (47%)

of these stakeholders, as compared to 21% for younger adults and 15% for older adults. Stakeholders representing younger SDP clients were also more likely to identify at least one specific *SDP Design Flaw* (47%), $\chi^2 = 6.65$, $p = .036$. Positively, stakeholders associated with younger SDP clients were significantly more likely to express benefiting from *Independent Facilitator Support* (42%), $\chi^2 = 10.09$, $p = .006$, *Better Access* (37%), $\chi^2 = 9.69$, $p = .008$, and *Better Rates for Service Providers* (26%), $\chi^2 = 11.70$, $p = .003$, than adults (0-16%). Although no other significant differences in thematic presence emerged, these findings generally suggest that navigating the SDP may be particularly challenging for minor aged clients and their families, with great potential benefits.

***Gender.*** Due to significant gender differences by participant type, such that more male current SDP participants than female current participants completed the qualitative survey, while more female family members completed the qualitative survey than male family members, $\chi^2 = 8.54$, $p = .003$, results for participants and family members were analyzed separately. For enrolled participants responding for themselves, female participants were significantly more likely (28%) than males (2%) to express the theme of *Challenges with SDP Staff Capacity and Professionalism*, $\chi^2 = 9.78$, $p = .002$. However, females were also more likely than males to report that SDP granted them greater *Freedom and Authority to Choose Services and Supports* (females: 88%; males: 55%), $\chi^2 = 7.85$, $p = .005$, and allowed them access to *Tailored/Individualized Services* (females: 24%, males: 0%), $\chi^2 = 11.07$, $p < .001$. No other gender differences among self-respondents emerged within the qualitative survey. With respect to family members of current SDP participants, female family members were significantly more likely to express a wide variety of themes, positive and negative. Though this may represent a difference in experience, it is more likely a function of response style, given that female family members' written responses were more than twice as long as male family members of current participants, $t(83) = -3.35$, $p = .001$.

***Diagnosis.*** Regional centers serve a variety of different populations of individuals with developmental disabilities. The most common diagnosis within the DDS system is intellectual disability (ID). Individuals with ID and their family members were more likely than other disability populations to describe experiencing *Delays and Gaps in Services* while enrolling or participating in the SDP, $\chi^2 = 5.72$, $p = .017$, with 18% of participants with ID being coded for this theme and only 5% of those without ID. It is possible that participants with ID may need more intensive supports to manage the paperwork and processes within the SDP to enroll in the program, ensure providers are set up with the FMS, and services are accessed in a timely fashion. Positively, participants with ID and their families more frequently expressed gratitude for the ability to offer *Better Rates for Providers* through the program, $\chi^2 = 6.31$, $p = .012$. 14% Fourteen percent of participants with ID and their families were coded for this theme as compared to 3% of those without ID. Given the potential higher intensity of support needs for individuals with ID, this benefit of the SDP may be particularly impactful for this population. No significant differences emerged for those with Cerebral Palsy or for those with Epilepsy on the presence of any themes.

Similar to participants with ID, autistic participants and their families were also more likely to highlight benefits related to paying *Better Rates for Providers*, $\chi^2 = 4.77$, $p = .029$, than other populations. Given that a proportion of these participants in the current sample also have intellectual disability, there may be overlap in this finding. However, in addition, autistic participants and their family members were significantly more likely to encounter challenges around *Lack of Staff Training and Knowledge*, $\chi^2 = 4.67$, $p = .031$, and *SDP Staff Capacity and Professionalism*, $\chi^2 = 3.85$, $p = .050$. Unfortunately, autistic participants and their families were also marginally less likely to be coded for the theme of *Overall Satisfaction with SDP*, $\chi^2 = 3.79$, $p = .051$. Specifically, while 59% of non-autistic respondents and their families expressed the theme of overall satisfaction, only 43% of autistic respondents and their families did so. These findings suggest that SDP staff, including regional center Staff, FMS Staff, and Independent Facilitators, may benefit from specialized training on supporting and interacting with autistic individuals.

# DISCUSSION

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. To address these challenges, we look to the recommendations offered by participants in this program evaluation. Thus, the following recommendations describe how the system could be administered more effectively. *In short, participants felt that the problem with SDP is not the concept or its principles, but the administrative burden.* In order to build on the promise of SDP, the state should consider changes to the design and implementation of SDP to more effectively advance the statutory goals of SDP for current and future participants.

## Recommendations

The below recommendations are organized in two ways: (1) experientially: as a person learns about SDP, proceeds through the steps to transition into SDP, and then is in SDP; and (2) at a systems level, as some recommendations cut across each stage of participants’ experiences with the program, such as how to create a more equitable system. Lastly, we note that implementing a new program is a constantly evolving process, and people surveyed identified challenges and suggested solutions that reflect where the program is *at this point in its development*.

### Stage-Based Recommendations

***Interested Stage: Improving Access to Information:*** To improve the SDP and meet the needs of individuals who are interested in enrolling in SDP, we identify four key areas related to information access: requiring regional centers to share information about SDP, enhancing outreach and awareness efforts, improving capacity for peer counseling, and developing clear and accessible guidance materials.

***Requiring Regional Centers to Share Information about SDP:*** Many participants learned about the SDP from regional centers. We recommend that regional centers be required to describe the SDP along with other service options to people who are new to the regional center system as part of standard orientation/intake, be provided materials, and offered the choice of the SDP during the IPP process.

***Enhancing Outreach and Awareness Efforts:*** A significant number of people heard about the SDP through informal networks. We recommend that the capacity of information sharing through informal networks be enhanced with targeted outreach and materials about the SDP. Targeted outreach can include the creation of community-specific brochures, a professionally produced video featuring success stories, and content designed to be shared through social media. Outreach materials should be created to engage BIPOC communities and in multiple languages. Targeted outreach can also include efforts to educate actors outside of the regional center system, such as professionals in fields like occupational therapy, speech therapy, and physical therapy.

***Improving Capacity for Peer Counseling:*** To overcome barriers faced by interested participants, such as lack of information about the SDP, administrative hurdles, and materials not tailored to individual circumstances, we recommend enhancing the capacity for SDP counseling. This capacity could be built within existing peer groups, such as family advocacy groups and self-advocacy groups. While group presentations and advertising were generally positively viewed, personalized materials and individualized peer-to-peer counseling are essential to ensure that all participants, including underserved groups, can determine whether SDP aligns with their specific needs. Peer counseling should be designed to increase access and support for BIPOC participants and in multiple languages.

***Developing Clear and Accessible Guidance Materials*****:** Respondents reported getting different information about SDP depending on the source. We recommend DDS and regional centers work together to develop a comprehensive set of guidance materials, offering step-by-step instructions and explanations of the SDP. These materials should use plain language, define acronyms, and include clear visuals to facilitate understanding. The materials should be available in multiple languages. An electronic guide, easily accessible both online and in physical form, can provide individuals with the necessary information to navigate the program effectively.

**Enrollment Stage:**

***Streamlining the Entry Process***. Based on respondents' concerns about the burdensome, time-consuming, and confusing enrollment process, we recommend streamlining the information and application process in the following ways. First, the enrollment process should be simplified and made more straightforward. Steps that are not statutorily required should be combined or eliminated where possible. To the extent either DDS or regional centers want to add steps beyond those required by statute, they should be required to demonstrate that the steps are designed to increase program access and equity. Second, clear timelines and deadlines should be established for each stage of the program to provide transparency and accountability and to ensure that individuals can progress through the program efficiently and with confidence. We recognize this effort is underway and look forward to its implementation. Third, the enrollment process should be accompanied with plain language and visual explanations to enhance comprehension and accessibility. Lastly, the request from respondents to have consistent rules and processes across regional centers could be done by strengthening the oversight role of DDS. This would promote fairness and equitable opportunities for participants throughout the state.

**Budgeting Stage:**

***Standardizing for Efficiency and Consistency***. Noting the critical role that adequate budgets and the freedom to reallocate funds play to advance the fundamental principles of the SDP, we recommend improving efficiency and consistency in the budgeting stage, including standardizing the approach to how individualized budget amounts are determined, thereby preventing discrepancies, and removing the subjective judgment of regional center staff. Additionally, standardizing the budget process and policies for the FMS vendors would further contribute to streamlining operations and enhancing overall efficiency.

**FMS Stage:**

**Increasing FMS Rates and Streamlining Pathway to Enrollment**. To address the needs of individuals at this stage of the program, recommendations from respondents included increasing FMS rates and streamlining the pathway to enrollment by reducing unnecessary steps to facilitate a more efficient process. Other themes, which are consistent throughout this report, centered on developing plain language and visual explanations related to the FMS process, establishing clear timelines and deadlines to ensure transparency and accessibility, and strengthening the oversight of DDS to reinforce consistent rules and processes across all regional centers, including the FMS stage. We note that FMS rates were increased effective May 1, 2023. This change helped to ensure uniformity and eliminated confusion and discrepancies across regional centers and FMS agencies. Higher FMS rates tend to support sustainability of the SDP program overall.

**Getting Services in SDP:**

Once in the program, we recommend changes to make specific implementation components more seamless and effective by taking obligations that are currently placed on individual participants, IFs and/or service coordinators, and instead operationalizing them as systemwide functions or administrative activities.

***Provide More Guidance on Spending Plans.*** To promote equity and clarity, we recommend establishing consistent, more detailed, and robust guidance regarding the kinds of expenditures allowed in spending plans. While some participants recommended establishing lists of permissible expenses, it is important to preserve the hallmark of the SDP, which is flexibility and individualization. Any such list should also define expenditures as those that promote key HCBS values, such as mobility and independence at home, or the cultivation of valued roles in the community and circles of support through shared special interests.

***Establish a Publicly Available Service Provider Directory or Virtual Resource Binder.*** We recommend a widely available directory of people who are willing to provide services to people within SDP. This would help participants find available providers by characteristics such as geography, the type of support provided, and/or language background and cultural competency. This directory could help address difficulties in locating direct support staff and activities that are both available and appropriate for an individual's needs. This directory should be done in a way that preserves and enhances the freedom to choose diverse types of services and select their own service providers.

***Clarify and Support the Roles of Systems Navigators.*** Participants expressed the need for specialized system navigators to assist anyone encountering difficulties in accessing the SDP. This is notable because in some ways, IFs and the SDP Ombudsperson already play such roles. However, structural limitations on both restrict their full availability and usefulness. IFs can provide invaluable service navigation to their clients in SDP but are available only to those who have chosen to allocate part of their budget to ongoing IF services. IF support is available to SDP participants with lower budget amounts, but in practice is often not utilized by those who feel that they cannot afford to allocate limited funds to IF support or would like to but cannot afford to do so. In contrast, the SDP Ombudsperson *is* available to anyone experiencing difficulties accessing services in SDP. However, by statute, the Ombudsperson is not designed to advocate for or provide direct support to SDP participants in the manner that is often required to overcome service access barriers. While the SDP Ombudsperson can be a valuable resource for general SDP information and suggestions, that office is not tasked with providing the kind of dedicated service navigation that participants want. To address this gap in need, we recommend expanding the affordability and accessibility of IFs as described above, restructuring the role and/or resources of the SDP Ombudsperson office to enable it to provide more dedicated problem-solving support, or similar systems-level changes.

## Systems-Level Recommendations

### Workforce

**Leverage the SDP to Improve Workforce Recruitment, Hiring, and Retention.** Many respondents cited the ability to negotiate and pay higher rates to providers they employ as one of the most valuable components of the SDP model. The ability to set and pay rates higher than the standard rates set by DDS and regional centers can be critical to finding appropriate support, especially for those with more complex behavioral or health needs, individuals in more rural or sparsely populated areas, monolingual speakers of languages other than English, and other groups that have typically struggled to find, hire, and retain staff at standard rates. The ability to hire non-vendored staff, such as family and friends, to provide support in SDP also helps ease the current workforce shortage and increases the amount of people providing culturally appropriate services. The SDP's potential to improve overall workforce recruitment, hiring, and retention in the DD system has gone largely underutilized. We recommend developing efforts aimed at using these hiring and rate setting flexibilities to gather data on and try out pilot projects regarding new or innovative service types or service code bundles that may be more effective at increasing the number of providers available to serve traditionally underserved groups. SDP's value as a relatively untapped workforce pipeline could also be better leveraged by targeting workforce development initiatives to non-traditional entry-level workers in the SDP specifically, who may not have otherwise considered a career as a HCBS provider but might do so given the right type and amount of support and incentives.

### Independent Facilitators:

***Improve Compensation and Capacity***. For individuals working with IFs in the SDP, several important considerations arise. Respondents appreciated having an IF as a supportive presence in the program but noted concerns related to staff capacity and professionalism, lack of staff training and knowledge, as well as the insufficient number of IFs, particularly in underserved communities, that create obstacles within the program. Furthermore, we note that Independent Facilitators often struggle with inadequate compensation for their services. We recommend improving capacity, training, and compensation, which will improve the overall quality of support provided by Independent Facilitators.

***Enhance IF Compensation***: We recommended modifying the SDP statute to allow IFs' pay to be allocated as a specific line item when forming the SDP budget. This change would ensure that funding is allocated for IF compensation, enabling participants to effectively hire and utilize paid Independent Facilitators.

***Ensure an Adequate Network of Independent Facilitators:*** To strengthen IF capacity, we recommend that the state invest in their development, with a particular focus on recruiting IFs from underrepresented communities, including BIPOC and individuals proficient in languages other than English. Establishing core IF competencies would ensure consistency and quality across different regional centers. Recent DDS directives have capped both the hourly rates for IFs and the number of hours that allocated for developing initial Person-Centered Plans, which support individuals transitioning into SDP. Some IFs have expressed concern that both caps are too low to allow them to adequately provide the necessary support and person-centered planning needed for individuals to enter the program. We recommend DDS track the impact of these caps on access to high quality IFs, other providers of transition supports, and person-centered planning overall. Should the data indicate a drop in the number and/or quality of person-centered plans, transition supports or individuals seeking to enter the SDP, DDS should revise their approach accordingly.

**Creating A More Equitable System:**

***Tailoring Supports to Underserved Communities.*** Across all of the barriers, racial and ethnic disparities persist in who can benefit from the SDP. To address this issue effectively, we recommend exploring strategies to mitigate the existing disparities within the SDP. This may involve developing targeted outreach campaigns to raise awareness about the program within historically underserved and unserved communities. This may also include SDP navigators who share participants' preferred culture and/or language. Additionally, efforts should be made to expand the pool of providers who can meet unique cultural and linguistic needs. Service Access and Equity grants could be targeted for SDP interventions. Implementing measures to ensure equitable distribution of resources and services, such as increased funding or incentives for providers serving historically underserved areas, could also help reduce the current disparities.

As participants discussed, the SDP has the potential to address some of the longstanding disparities in California’s developmental disabilities system. However, that potential has largely remained unrealized. To address these disparities, we propose tailoring support to the needs of underserved groups while working to decrease administrative burden, which disproportionately harms people of color, people with a first language other than English, and people with limited financial resources. For each of the above recommendations, we recommend building capacity to support underserved communities in the SDP. This should include outreach, peer counseling, workforce development, and IF capacity-building.

## 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.

- First, input from self-advocates and family members showed that there is a lack of information and buy-in from regional center service coordinators. More research should be done to understand why service coordinators are resistant to this model and how to inform them of its key role in the landscape of developmental disability service delivery.

- Although this study was able to collect demographic information, we were unable to collect detail on whether the reported barriers were unequally felt by different racial and ethnic groups. Several respondents discussed equity concerns, and future research should better assess this issue. Additionally, this research revealed the SDP is harder to navigate for Autistic and younger people. Additional research in these areas could uncover the causes and solutions.

- A comparative analysis could be done about experiences and outcomes of people in the SDP and people in traditional services. While this study revealed a few differences, a study focused on the experiences of people in the two programs would reveal the extent of those differences.

- Lastly, some of the concerns discussed by participants were not unique to the SDP and were experienced across in the traditional service delivery model as well. For example, incomplete needs assessments and lack of person-centeredness were identified as problems within the overall system. Participants mentioned difficulty determining and/or reaching agreement with service coordinators regarding individuals’ unmet needs, which contributed to delays in finalizing initial budget amounts and entry into SDP. Future research should explore potential ways to assess need, including but not limited to unmet need, more consistently and systematically. Additionally, further consideration should also be given incentivizing the growth of SDP and initiatives aimed at increasing people’s ability to make decisions and exercise autonomy over their own lives on a system-wide basis.

# CONCLUSION

This program evaluation highlights the strengths of the SDP: its unique ability to empower individuals to direct their own services and the flexibility, independence, and customization that it offers. Participants within and outside of the SDP have emphasized that these values were of high priority in their lives.

Although self-directed services require administrative work, we are concerned by the immense administrative burdens reported by the study participants. This level of administrative burden is not inherent to self-directed waivers, as we can see from the national context detailed above. Our developmental disabilities service delivery system needs to adjust to shift this burden off participants, and where possible, remove unnecessary steps. Tools like standardization can help streamline the system, while system navigators can help people find their way in the current process. Because these barriers disproportionately affect underserved groups, such as people of color and people with a first language other than English, addressing administrative burden will also make the system more equitable. The principles of self-determination improve lives; therefore, they need to be made available to all Californians with intellectual and/or developmental disabilities, not only a select privileged few able to navigate the current, inequitable system.

# APPENDIX TABLE OF CONTENTS

Appendix 1. Survey Questions

Appendix 2. SDP Flow Chart

Appendix 3. Glossary of Terms

Appendix 4. Welfare and Institutions Code

**Appendix 1.**

## Questions asked in Virtual Focus Groups and Qualitative Survey

*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?

**Appendix 2.**

CALIFORNIA
SCDD
State Council on Developmental Disabilities

# DDS SELF-DETERMINATION PROGRAM

## How To Get Started:

### 1 Attend an Orientation

After the Orientation, tell your Service Coordinator if you want to join the Self-Determination Program (SDP).

### 2 Person-Centered Planning

Gather your SDP team (family, friends, teachers, providers, etc).

Develop a Person-Centered Plan with your team and update your IPP.

### 3 Budget

Develop a budget from IPP goals & needed services and supports.

Get a final budget approved by Regional Center.

### 4 Select FMS Model

Create and review your spending plan.

Arrange services and supports from qualified people or businesses.

### 5 Enroll in SDP & Start Services

Finalize spending plan and services.

Confirm that all services are in both Regional Center and FMS accounting systems.

**Appendix 3.**

# Glossary of Terms

## Glossary of Terms

The following terms hold specific meanings in the context of the Self-Determination Program (SDP) representing key entities and elements within the California Self-Determination Program, highlighting the collaboration, oversight, and coordination necessary to ensure the successful implementation of the program and the provision of individualized supports and services to program participants.

### Budget and Spending Plan

The Budget and Spending Plan are integral components of the Self-Determination Program. Participants are allocated an individual budget, which refers to the amount of funding allocated to them to support their services and supports. The Budget outlines the overall funding available to the participant, while the Spending Plan is a detailed breakdown that specifies how the participant plans to allocate and spend their budget across various services and supports based on their individual needs and goals.

### DDS: California Department of Developmental Services

The California Department of Developmental Services (DDS) is the state agency responsible for overseeing and implementing services and supports for individuals with developmental disabilities. DDS plays a crucial role in establishing program guidelines, providing guidance to regional centers, and ensuring the effective implementation of the Self-Determination Program.

### FMS: Financial Management Service Provider

A Financial Management Service (FMS) provider is an entity approved by the California Department of Developmental Services (DDS) to offer financial management services to participants in the Self-Determination Program. FMS providers assist participants in managing their individual budgets, handling financial transactions, and ensuring compliance with program guidelines. They play a crucial role in helping participants effectively allocate and track their funds while maintaining transparency and accountability.

### IF: Independent Facilitator

An Independent Facilitator (IF) is either a volunteer or paid supporter who guides individuals with developmental disabilities in their decision-making and person-centered planning processes. The IF works closely with the participant, ensuring that their voice and preferences are central to the planning and implementation of their Self-Determination Program. The IF provides guidance and assistance throughout the process, empowering the participant to exercise self-determination and make informed choices.

### IPP: Individual Program Plan

The Individual Program Plan (IPP) is a comprehensive plan developed in collaboration with the participant, regional center (RC), and support service organization. It serves as a roadmap outlining the participant's goals, objectives, and the specific services to be provided, ensuring alignment with their preferences and needs. The IPP is designed to support the participant in achieving their desired outcomes and guiding the implementation of their individualized support and services for the year.

**LAC: Local Advisory Committees**

The Local Advisory Committees (LACs) play a significant role in supporting the implementation of the Self-Determination Program at the local level. LACs are established within each of the 21 regional centers (RCs) and are comprised of community members, individuals with developmental disabilities, family members, service providers, and other stakeholders. The primary function of LACs is to provide input, feedback, and recommendations on issues related to the Self-Determination Program within their respective geographic areas. They serve as a forum for collaboration and dialogue, allowing participants and their families to express their needs, concerns, and suggestions regarding the program. LACs play a crucial role in fostering community engagement, disseminating information, and promoting awareness of the Self-Determination Program. Their valuable insights and perspectives contribute to the ongoing improvement and success of the program at the local level, ensuring that it remains responsive and aligned with the needs of participants and the broader community.

**PCP: Person-Centered Planning**

Person-Centered Planning (PCP) is a fundamental process within the Self-Determination Program. It involves a collaborative approach where the participant, along with their chosen supporters and professionals, identify their unique preferences, strengths, needs, and goals. Through PCP, the participant takes an active role in shaping their IPP, ensuring that it reflects their individual aspirations and desired outcomes. “Person-centered planning is a framework for planning and making decisions. It is not a collection of methods or procedures. Person-centered planning is based on an awareness of, and sensitivity to, the lifestyle and cultural background of the consumer and family.” (Welfare & Institutions Code Section 4646.5(a)(1)).

**RC: Regional Center**

Regional Centers (RCs) are nonprofit organizations contracted by the DDS to provide services and supports to individuals with developmental disabilities in 21 different geographic areas throughout the state of CA. RCs play a key role in the Self-Determination Program by assisting participants with enrollment, person-centered planning, accessing services and supports, and coordinating resources within their designated regions.

**SC: Service Coordinator**

A Service Coordinator (SC) is from the participants' regional center (RC) and plays a vital role within the Self-Determination Program. The SC provides guidance and assistance to participants throughout their journey in the program. They may help with various aspects, including enrollment, person-centered planning, accessing services and supports, and navigating the program's requirements and processes. The RC acts as a point of contact for participants and is responsible for coordinating services and resources in their designated geographical area.

**SDP Ombudsperson: Self-Determination Program Ombudsperson.**
The SDP Ombudsperson serves as an independent advocate and resource for participants in the Self-Determination Program. The Ombudsperson provides information, guidance, and assistance regarding program rights, responsibilities, and dispute resolution. They help ensure that participants' concerns are addressed, and their rights are protected within the program.

**SSDAC: Statewide Self-Determination Advisory Committee.**
The Statewide Self-Determination Advisory Committee (SSDAC) is an integral component of the Self-Determination Program overseen by the State Council on Developmental Disabilities (SCDD). The SSDAC is composed of individuals with developmental disabilities, family members, advocates, and stakeholders who are the chair or designee of their Local Advisory Committee (LAC). Its purpose is to provide recommendations, advice, and feedback to SCDD and DDS on matters related to the Self-Determination Program.

**Appendix 4**

# Statutory Requirements (WIC)

## WELFARE AND INSTITUTIONS CODE - WIC
## DIVISION 4.5. SERVICES FOR THE DEVELOPMENTALLY DISABLED [4500 - 4885]

**4685.8**.

(a) The department shall implement a statewide Self-Determination Program. The Self-Determination Program shall be available in every regional center catchment area to provide participants and their families, within an individual budget, increased flexibility and choice, and greater control over decisions, resources, and needed and desired services and supports to implement their IPP. As of July 1, 2021, the program shall begin to be available on a voluntary basis to all regional center consumers who are eligible for the Self-Determination Program.

(b) The department, in establishing the statewide program, shall do both of the following:

(1) Set targets and benchmarks as set forth in paragraph (1) of subdivision (r).

(2) Address all of the following:

(A) Oversight of expenditure of self-determined funds and the achievement of participant outcomes over time.

(B) Increased participant control over which services and supports best meet the participant’s needs and the IPP objectives. A participant’s unique support system may include the purchase of existing service offerings from service providers or local businesses, hiring their own support workers, or negotiating unique service arrangements with local community resources.

(C) Comprehensive person-centered planning, including an individual budget and services that are outcome based.

(D) Consumer and family training to ensure understanding of the principles of self-determination, the planning process, and the management of budgets, services, and staff.

(E) Choice of independent facilitators, who meet standards and certification requirements established by the department, and who can assist with the functions specified in paragraph (2) of subdivision (c).

(F) Choice of financial management services providers who meet standards and certification requirements established by the department, and who can carry out the functions specified in paragraph (1) of subdivision (c).

(G) Innovation that will more effectively allow participants to achieve their goals.

(H) Long-term sustainability of the Self-Determination Program by doing all of the following:

(i) Requiring IPP teams, when developing the individual budget, to determine the services, supports and goods necessary for each consumer based on the needs and preferences of the consumer, and when appropriate the consumer’s family, and the effectiveness of each option in meeting the goals specified in the IPP, and the cost effectiveness of each option, as specified in subparagraph (D) of paragraph (6) of subdivision (a) of Section 4648.

(ii) The department may review final individual budgets that are at or above a spending threshold determined by the department of all individual budgets and use information from its review in the aggregate to develop additional program guidance and verify compliance with federal and state laws and other requirements.

(c) For purposes of this section, the following definitions apply:

(1) “Financial management services” means services or functions that assist the participant to manage and direct the distribution of funds contained in the individual budget, and ensure that the participant has the financial resources to implement their IPP throughout the year. These may include bill paying services and activities that facilitate the employment of service and support workers by the participant, including, but not limited to, fiscal accounting, tax withholding, compliance with relevant state and federal employment laws, assisting the participant in verifying provider qualifications, including criminal background checks, and expenditure reports. The financial management services provider shall meet the applicable requirements of Title 17 of the California Code of Regulations and other specific qualifications or certifications established by the department.

(2) “Independent facilitator” means a person, selected and directed by the participant, who is not otherwise providing services to the participant pursuant to their IPP and is not employed by a person providing services to the participant. The independent facilitator may assist the participant in making informed decisions about the individual budget, and in locating, accessing, and coordinating services and supports consistent with the participant’s IPP. The independent facilitator is available to assist in identifying immediate and long-term needs, developing options to meet those needs, leading, participating, or advocating on behalf of the participant in the person-centered planning process and development of the IPP, and obtaining identified services and supports. The cost of the independent facilitator, if any, shall be paid by the participant out of the participant’s individual budget. An independent facilitator shall receive training in the principles of self-determination, the person-centered planning process, and the other responsibilities described in this paragraph at the independent facilitator’s own cost. The independent facilitator shall meet standards and certification requirements established by the department.

(3) “Individual budget” means the amount of regional center purchase of service funding available to the participant for the purchase of services and supports necessary to implement the IPP. The individual budget shall be determined using a fair, equitable, and transparent methodology.

(4) “IPP” means individual program plan, as described in Section 4646.

(5) “Participant” means an individual, and when appropriate, the participant’s parents, legal guardian or conservator, or authorized representative, who has been deemed eligible for, and has voluntarily agreed to participate in, the Self-Determination Program.

(6) “Self-determination” means a voluntary delivery system consisting of a defined and comprehensive mix of services and supports, selected and directed by a participant through person-centered planning, in order to meet the objectives in their IPP. Self-determination services and supports are designed to assist the participant to achieve personally defined outcomes in community settings that promote inclusion. The Self-Determination Program shall only fund services and supports provided pursuant to this division that the federal Centers for Medicare and Medicaid Services determines are eligible for federal financial participation.

(7) “Spending Plan” means the plan the participant develops to use their available individual budget funds to purchase goods, services, and supports necessary to implement their individual program

plan (IPP). The spending plan shall identify the cost of each good, service, and support that will be purchased with regional center funds. The total amount of the spending plan cannot exceed the amount of the individual budget. A copy of the spending plan shall be attached to the participant's IPP.

(d) Participation in the Self-Determination Program is fully voluntary. A participant may choose to participate in, and may choose to leave, the Self-Determination Program at any time. A regional center shall not require or prohibit participation in the Self-Determination Program as a condition of eligibility for, or the delivery of, services and supports otherwise available under this division. Participation in the Self-Determination Program shall be available to any regional center consumer who meets the following eligibility requirements:

(1) The participant has a developmental disability, as defined in Section 4512, and is receiving services pursuant to this division.

(2) The consumer does not live in a licensed long-term health care facility, as defined in paragraph (44) of subdivision (a) of Section 54302 of Title 17 of the California Code of Regulations. An individual, and when appropriate the individual's parent, legal guardian or conservator, or authorized representative, who is not eligible to participate in the Self-Determination Program pursuant to this paragraph may request that the regional center provide person-centered planning services in order to make arrangements for transition to the Self-Determination Program, provided that the individual is reasonably expected to transition to the community within 90 days. In that case, the regional center shall initiate person-centered planning services within 60 days of that request.

(3) The participant agrees to all of the following terms and conditions:

(A) The participant shall receive an orientation that meets the standards set or developed by the department to the Self-Determination Program prior to enrollment, which includes the principles of self-determination, the role of the independent facilitator and the financial management services provider, person-centered planning, and development of a budget.

(B) The participant shall utilize the services and supports available within the Self-Determination Program only when generic services and supports are not available.

(C) The participant shall only purchase services and supports necessary to implement their IPP and shall comply with any and all other terms and conditions for participation in the Self-Determination Program described in this section.

(D) The participant shall manage Self-Determination Program services and supports within the participant's individual budget.

(E) The participant shall utilize the services of a financial management services provider of their own choosing and who is vendored by a regional center and who meets the qualifications in paragraph (1) of subdivision (c).

(F) The participant may utilize the services of an independent facilitator of their own choosing for the purpose of providing services and functions as described in paragraph (2) of subdivision (c). If the participant elects not to use an independent facilitator, the participant may use their regional center service coordinator to provide the services and functions described in paragraph (2) of subdivision (c).

(G) If eligible, with the assistance of the regional center, if needed, timely apply for Medi-Cal in order to maximize federal funding. The participant may consider institutional deeming in order to qualify for Medi-Cal services.

(e) A participant who is not Medi-Cal eligible may participate in the Self-Determination Program and receive self-determination services and supports if all other program eligibility requirements are met and the services and supports are otherwise eligible for federal financial participation.

(f) The additional federal financial participation funds generated by the former participants of the self-determination pilot projects authorized pursuant to Section 13 of Chapter 1043 of the Statutes of 1998, as amended, or pursuant to Article 4 (commencing with Section 4669.2) of Chapter 5, shall be used to maximize the ability of Self-Determination Program participants to direct their own lives and to ensure the department and regional centers successfully implement the program as follows:

(1) First, to offset the cost to the department for the criminal background check conducted pursuant to subdivision (v) and other administrative costs incurred by the department in implementing the Self-Determination Program.

(2) With the remaining funds, the department, in consultation with stakeholders, including a statewide self-determination advisory workgroup, shall prioritize the use of the funds to meet the needs of participants, increase service access and equity, and reduce disparities, and to implement the program, including costs associated with all of the following:

(A) Independent facilitators to assist with a participant’s initial person-centered planning meeting.

(B) Development of the participant’s initial individual budget.

(C) Joint training of consumers, family members, regional center staff, and members of the local volunteer advisory committee established pursuant to paragraph (1) of subdivision (w).

(D) Regional center operations to increase support for transition to the Self-Determination Program or for caseload ratio enhancement.

(E) To offset the costs to the regional centers in implementing the Self-Determination Program.

(F) To support the Statewide Self-Determination Advisory Committee established pursuant to paragraph (2) of subdivision (w).

(g) If at any time during participation in the Self-Determination Program a regional center determines that a participant is no longer eligible to continue in, or a participant voluntarily chooses to exit, the Self-Determination Program, the regional center shall provide for the participant’s transition from the Self-Determination Program to other services and supports. This transition shall include the development of a new IPP that reflects the services and supports necessary to meet the individual’s needs. The regional center shall ensure that there is no gap in services and supports during the transition period.

(h) An individual determined to be ineligible for or who voluntarily exits the Self-Determination Program shall be permitted to return to the Self-Determination Program upon meeting all applicable eligibility criteria and upon approval of the participant’s planning team, as described in subdivision (j) of Section 4512. An individual who has voluntarily exited the Self-Determination Program shall not return to the program for at least 12 months.

(i) An individual who participates in the Self-Determination Program may elect to continue to receive self-determination services and supports if the individual transfers to another regional center catchment area, provided that the individual remains eligible for the Self-Determination Program pursuant to subdivision (d). The balance of the participant’s individual budget shall be reallocated to the regional center to which the participant transfers.

(j) The IPP team shall utilize the person-centered planning process to develop the IPP for a participant. The IPP shall detail the goals and objectives of the participant that are to be met through the purchase of participant-selected services and supports. The IPP team shall determine the individual budget to ensure the budget assists the participant to achieve the outcomes set forth in the participant’s IPP and ensures their health and safety. The completed individual budget shall be attached to the IPP.

(k) The participant shall implement their IPP, including choosing and purchasing the services and supports allowable under this section necessary to implement the plan. A participant is exempt from the cost control restrictions regarding the purchases of services and supports pursuant to Section 4648.5. A regional center shall not prohibit the purchase of any service or support that is otherwise allowable under this section.

(l) A participant shall have all the rights established in Sections 4646 to 4646.6, inclusive, and Chapter 7 (commencing with Section 4700).

(m) (1) Except as provided in paragraph (4), the IPP team shall determine the initial and any revised individual budget for the participant using the following methodology:

(A) (i) Except as specified in clause (ii), for a participant who is a current consumer of the regional center, their individual budget shall be the total amount of the most recently available 12 months of purchase of service expenditures for the participant.

(ii) An adjustment may be made to the amount specified in clause (i) if both of the following occur:

(I) The IPP team determines that an adjustment to this amount is necessary due to a change in the participant’s circumstances, needs, or resources that would result in an increase or decrease in purchase of service expenditures, or the IPP team identifies prior needs or resources that were unaddressed in the IPP, which would have resulted in an increase or decrease in purchase of service expenditures. When adjusting the budget, the IPP team shall document the specific reason for the adjustment in the IPP.

(II) The regional center certifies on the individual budget document that regional center expenditures for the individual budget, including any adjustment, would have occurred regardless of the individual’s participation in the Self-Determination Program.

(iii) For purposes of clauses (i) and (ii), the amount of the individual budget shall not be increased to cover the cost of the independent facilitator.

(B) For a participant who is either newly eligible for regional center services or who does not have 12 months of purchase service expenditures, the participant’s individual budget shall be calculated as follows:

(i) The IPP team shall identify the services and supports needed by the participant and available resources, as required by Section 4646.

(ii) The regional center shall calculate the cost of providing the services and supports to be purchased by the regional center by using the average cost paid by the regional center for each service or support unless the regional center determines that the consumer has a unique need that requires a higher or lower cost. The IPP team also shall document the specific reason for the adjustment in the IPP. The regional center shall certify on the individual budget document that this amount would have been expended using regional center purchase of service funds regardless of the individual's participation in the Self-Determination Program.

(iii) For purposes of clauses (i) and (ii), the amount of the individual budget shall not be increased to cover the cost of the independent facilitator.

(2) The amount of the individual budget shall be available to the participant each year for the purchase of program services and supports. An individual budget shall be calculated no more than once in a 12-month period, unless revised to reflect a change in circumstances, needs, or resources of the participant using the process specified in clause (ii) of subparagraph (A) of paragraph (1).

(3) The spending plan shall be assigned to uniform budget categories developed by the department in consultation with stakeholders and distributed according to the timing of the anticipated expenditures in the IPP and in a manner that ensures that the participant has the financial resources to implement the IPP throughout the year.

(4) The department, in consultation with stakeholders, may develop alternative methodologies for individual budgets that are computed in a fair, transparent, and equitable manner and are based on consumer characteristics and needs, and that include a method for adjusting individual budgets to address a participant's change in circumstances or needs.

(n) Annually, participants may transfer up to 10 percent of the funds originally distributed to any budget category set forth in paragraph (3) of subdivision (m) to another budget category or categories. Transfers in excess of 10 percent of the original amount allocated to any budget category may be made upon the approval of the regional center or the participant's IPP team.

(o) Consistent with the implementation date of the IPP, the IPP team shall annually ascertain from the participant whether there are any circumstances or needs that require a change to the annual individual budget. Based on that review, the IPP team shall calculate a new individual budget consistent with the methodology identified in subdivision (m).

(p) (1) The department, as it determines necessary, may adopt regulations to implement the procedures set forth in this section. Any regulations shall be adopted in accordance with the requirements of Chapter 3.5 (commencing with Section 11340) of Part 1 of Division 3 of Title 2 of the Government Code.

(2) Notwithstanding paragraph (1) and Chapter 3.5 (commencing with Section 11340) of Part 1 of Division 3 of Title 2 of the Government Code, and only to the extent that all necessary federal approvals are obtained, the department, without taking any further regulatory action, shall implement, interpret, or make specific this section by means of program directives or similar instructions until the time regulations are adopted. It is the intent of the Legislature that the department be allowed this temporary authority as necessary to implement program changes only until completion of the regulatory process.

(q) The department, in consultation with stakeholders, shall develop informational materials about the Self-Determination Program. The department shall ensure that regional centers are trained in the principles of self-determination, the mechanics of the Self-Determination Program, and the rights of consumers and families as candidates for, and participants in, the Self-Determination Program.

(r) Each regional center shall be responsible for implementing the Self-Determination Program as a term of its contract under Section 4629. As part of implementing the program, the regional center shall do all of the following:

(1) Meet the Self-Determination targets approved by the department, meet benchmarks established by the department in areas including timely enrollment, diversity of consumers served, and reduction of disparities in the individual budget of participants from racial and ethnic communities, and be eligible for incentives for exceeding these targets and benchmarks once the department has established a performance incentives program.

(2) Develop and implement an outreach and training plan about the Self-Determination program for the diverse communities served by the regional center, including in congregate settings. Information shall be provided in plain language, in alternative formats and alternative modes of communication and provide language access as required by state and federal law. Obtain input from stakeholders, including consumers and families that reflect the ethnic and language diversity of the regional center’s consumers, about the effectiveness of this outreach and training and other activities that may be effective in reducing disparities in these programs.

(3) Annually report the enrollment, individual budget data, and purchase of service expenditure data for the Self-Determination Program consistent with the criteria in subdivisions (a) to (c), inclusive, of Section 4519.5.

(4) Assist eligible participants and their families in applying for Medi-Cal, in order to maximize federal funding and assist interested participants who wish to pursue institutional deeming in order to qualify for Medi-Cal services.

(5) At least annually, in addition to annual certification, conduct an additional review of all final individual budgets for participants at the regional center which are at or above a spending threshold that is specified by the department through directive consistent with federal and state requirements. This information may be used in the aggregate to provide training, program guidance, and verify compliance with state and federal requirements.

(6) Review the spending plan to verify that goods and services eligible for federal financial participation are not used to fund goods or services available through generic agencies.

(7) Contract with local consumer or family-run organizations and consult with the local volunteer advisory committee established pursuant to paragraph (1) of subdivision (w) to conduct outreach through local meetings or forums to consumers and their families to provide information about the Self-Determination Program and to help ensure that the program is available to a diverse group of participants, with special outreach to underserved communities.

(8) Collaborate with the local consumer or family-run organizations identified in paragraph (1) to jointly conduct training about the Self-Determination Program. The regional center shall consult with the local volunteer advisory committee established pursuant to paragraph (1) of subdivision (w) in planning for the training, and the local volunteer advisory committee may designate members to represent the advisory committee at the training.

(9) Train all service coordinators and fair hearing specialists in the principles of self-determination, the mechanics of the Self-Determination Program, and the rights of consumers and families. The training shall be conducted in collaboration with the local volunteer advisory committee.

(10) Provide payment to the financial management services provider for spending plan expenses through a not less than semi-monthly pay schedule.

(s) The financial management services provider shall provide the participant and the regional center service coordinator with a monthly individual budget statement that describes the amount of funds allocated by budget category, the amount spent in the previous 30-day period, and the amount of funding that remains available under the participant’s individual budget.

(t) Only the financial management services provider is required to apply for vendorization in accordance with Subchapter 2 (commencing with Section 54300) of Chapter 3 of Division 2 of Title 17 of the California Code of Regulations for the Self-Determination Program. All other service and support providers shall not be on the federal debarment list and shall have applicable state licenses, certifications, or other state required documentation, including documentation of any other qualifications required by the department, but are exempt from the vendorization requirements set forth in Title 17 of the California Code of Regulations when serving participants in the Self-Determination Program.

(u) The regional center shall pay the full costs of the participant’s financial management services provider.

(v) To protect the health and safety of participants in the Self-Determination Program, the department shall require a criminal background check in accordance with all of the following:

(1) The department shall issue a program directive that identifies nonvendored providers of services and supports who shall obtain a criminal background check pursuant to this subdivision. At a minimum, these staff shall include both of the following:

(A) Individuals who provide direct personal care services to a participant.

(B) Other nonvendored providers of services and supports for whom a criminal background check is requested by a participant or the participant’s financial management service.

(2) Subject to the procedures and requirements of this subdivision, the department shall administer criminal background checks consistent with the department’s authority and the process described in Sections 4689.2 to 4689.6, inclusive.

(3) The department shall electronically submit to the Department of Justice fingerprint images and related information required by the Department of Justice of nonvendored providers of services and supports, as specified in paragraph (1), for purposes of obtaining information as to the existence and content of a record of state or federal convictions and state or federal arrests and also information as to the existence and content of a record of state or federal arrests for which the Department of Justice establishes that the person is free on bail or on their own recognizance pending trial or appeal.

(4) When received, the Department of Justice shall forward to the Federal Bureau of Investigation requests for federal summary criminal history information received pursuant to this section. The Department of Justice shall review the information returned from the Federal Bureau of Investigation and compile and disseminate a response to the department.

(5) The Department of Justice shall provide a state or federal response to the department pursuant to paragraph (1) of subdivision (p) of Section 11105 of the Penal Code.

(6) The department shall request from the Department of Justice subsequent notification service, as provided pursuant to Section 11105.2 of the Penal Code, for persons described in paragraph (1).

(7) The Department of Justice shall charge a fee sufficient to cover the cost of processing the request described in this subdivision.

(8) The fingerprints of any provider of services and supports who is required to obtain a criminal background check shall be submitted to the Department of Justice prior to employment. The costs of the fingerprints and the financial management service's administrative cost authorized by the department shall be paid by the services and supports provider or the provider's employing agency. Any administrative costs incurred by the department pursuant to this subdivision shall be offset by the funds specified in subdivision (g).

(9) If the criminal record information report shows a criminal history, the department shall take the steps specified in Section 4689.2. The department may prohibit a provider of services and supports from becoming employed, or continuing to be employed, based on the criminal background check, as authorized in Section 4689.6. The provider of services and supports who has been denied employment shall have the rights set forth in Section 4689.6.

(10) The department may utilize a current department-issued criminal record clearance to enable a provider to serve more than one participant, as long as the criminal record clearance has been processed through the department and no subsequent arrest notifications have been received relative to the cleared applicant.

(11) Consistent with subdivision (h) of Section 4689.2, the participant or financial management service that denies or terminates employment based on written notification from the department shall not incur civil liability or unemployment insurance liability.

(w) To ensure the effective implementation of the Self-Determination Program and facilitate the sharing of best practices and training materials commencing with the implementation of the Self-Determination Program, local and statewide advisory committees shall be established as follows:

(1) Each regional center shall establish a local volunteer advisory committee to provide oversight of the Self-Determination Program and identify a regional center liaison to the committee. The regional center and the State Council on Developmental Disabilities shall each appoint one-half of the membership of the committee. The committee shall consist of the regional center clients' rights advocate, consumers, family members, and other advocates, and community leaders, including a representative from a family resource center. A majority of the committee shall be consumers and their family members. The committee shall reflect the multicultural diversity and geographic profile of the catchment area. The committee shall review the development and ongoing progress of the Self-Determination Program, including whether the program advances the principles of self-determination and is operating consistent with the requirements of this section, and may make ongoing recommendations for improvement to the regional center and the department. Annually, the regional center shall confirm, in writing, that the committee meets the requirements specified in this paragraph and provide the department with the name of the staff liaison and the names of the committee members, the positions they fill on the committee, and which entity appointed them to the committee.

(2) The State Council on Developmental Disabilities shall form a volunteer committee, to be known as the Statewide Self-Determination Advisory Committee, comprised of the chairs of the 21 local advisory committees or their designees. The council shall convene the Statewide Self-Determination Advisory Committee twice annually, or more frequently in the sole discretion of the council. The Statewide Self-Determination Advisory Committee shall meet by teleconference or other means established by the council to identify self-determination best practices, effective consumer and family training materials, implementation concerns, systemic issues, ways to enhance the program, and recommendations regarding the most effective method for participants to learn of individuals who are available to provide services and supports. The council shall synthesize information received from the Statewide Self-Determination Advisory Committee, local advisory committees, and other sources, share the information with consumers, families, regional centers, and the department, and make recommendations, as appropriate, to increase the program's effectiveness in furthering the principles of self-determination.

(x) The department shall annually provide the following information to the appropriate policy and fiscal committees of the Legislature:

(1) Number and characteristics of participants, by regional center, including the number of participants who entered the program upon movement from a developmental center.

(2) Types and amount of services and supports purchased under the Self-Determination Program, by regional center.

(3) Range and average of individual budgets, by regional center, including adjustments to the budget to address the adjustments permitted in clause (ii) of subparagraph (A) of paragraph (1) of subdivision (m).

(4) The number and outcome of appeals concerning individual budgets, by regional center.

(5) The number and outcome of fair hearing appeals, by regional center.

(6) The number of participants who voluntarily withdraw from the Self-Determination Program and a summary of the reasons why, by regional center.

(7) The number of participants who are subsequently determined to no longer be eligible for the Self-Determination Program and a summary of the reasons why, by regional center.

(y) (1) The State Council on Developmental Disabilities shall issue an interim report to the Legislature, in compliance with Section 9795 of the Government Code, no later than June 30, 2021, on the status of the Self-Determination Program authorized by this section, barriers to its implementation, and recommendations to enhance the effectiveness of the program. The interim report shall provide an update to the program's status, each regional center's cap on participation and progress toward that cap, the most recent statewide and per-regional-center participant count, and the historical trend in the statewide participation count since the start of the program. The department shall assist in providing available information to the council in order to facilitate the timely issuance of the report.

(2) The council, in collaboration with the protection and advocacy agency identified in Section 4900 and the federally funded University Centers for Excellence in Developmental Disabilities Education, Research, and Service, may work with regional centers to survey participants regarding participant satisfaction under the Self-Determination Program and, when data is available, the traditional service

delivery system, including the proportion of participants who report that their choices and decisions are respected and supported and who report that they are able to recruit and hire qualified service providers, and to identify barriers to participation and recommendations for improvement.

(3) The council, in collaboration with the protection and advocacy agency identified in Section 4900 and the federally funded University Centers for Excellence in Developmental Disabilities Education, Research, and Service, shall issue a report to the Legislature, in compliance with Section 9795 of the Government Code, by June 30, 2023, on the status of the Self-Determination Program authorized by this section, and provide recommendations to enhance the effectiveness of the program. This review shall include the program's effectiveness in furthering the principles of self-determination, including all of the following:

(A) Freedom, which includes the ability of adults with developmental disabilities to exercise the same rights as all citizens to establish, with freely chosen supporters, family and friends, where they want to live, with whom they want to live, how their time will be occupied, and who supports them; and for families to have the freedom to receive unbiased assistance of their own choosing when developing a plan and to select all personnel and supports to further the life goals of a minor child.

(B) Authority, which includes the ability of a person with a disability, or family, to control a certain sum of dollars in order to purchase services and supports of their choosing.

(C) Support, which includes the ability to arrange resources and personnel, both formal and informal, that will assist a person with a disability to live a life in the community that is rich in community participation and contributions.

(D) Responsibility, which includes the ability of participants to take responsibility for decisions in their own lives and to be accountable for the use of public dollars, and to accept a valued role in their community through, for example, competitive employment, organizational affiliations, spiritual development, and general caring of others in their community.

(E) Confirmation, which includes confirmation of the critical role of participants and their families in making decisions in their own lives and designing and operating the system that they rely on.

*(Amended by Stats. 2022, Ch. 49, Sec. 22. (SB 188) Effective June 30, 2022.)*