# REPORT SUBMISSION MEMO

**TO:** CHAIRS OF THE SELF-DETERMINATION LOCAL ADVISORY COMMITTEE

**FROM:** MARIA MARQUEZ AND RICK WOOD, SSDAC CO-CHAIRS

**SUBJECT:** STATEWIDE SELF-DETERMINATION ADVISORY COMMITTEE REPORT SUBMISSION

**DATE:** AUGUST 10, 2020

The Statewide Self-Determination Advisory Committee (SSDAC) hereby submits "*A Statewide Self-Determination Advisory Committee Report on the Barriers to Implementing the Self-Determination Program*."

SSDAC is a statutorily created advisory committee that is comprised of the chairs of the 21 local self-determination advisory committees and a member of the State Council on Developmental Disabilities (Council), to advise and make recommendations on ways to increase the effectiveness of the Self-Determination Program.

This report is the result of more than 18 months of research by SSDAC members to evaluate the implementation success of the Self-Determination Program which was signed into statute on October 7, 2013, by Governor Jerry Brown (Senate Bill [SB] 468). This program is based on a successful multiyear self-determination pilot project, which gave individuals with developmental disabilities authentic person-centered planning, choice and control over their services and supports, and better outcomes.

The SSDAC requests that as the chair of your local self-determination advisory committee, you use the report as the basis for your committee's discussion of barriers which exist in your regional center, and to assist your regional center in implementing its recommendations. We believe with your assistance, Californians with developmental disabilities and their families can truly become self-determined.

Thank you.


# A Statewide Self-Determination Advisory Committee Report on The Barriers to Implementing The Self-Determination Program

August 10, 2020

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# REPORT ON BARRIERS TO IMPLEMENTATION OF THE SELF-DETERMINATION PROGRAM AND RECOMMENDATIONS TO OVERCOME THEM

## Introduction

On October 7, 2013, a Statewide Self-Determination Program (SDP) was created by Governor Jerry Brown's signature of Senate Bill (SB) 468. It is based on successful multi-year self-determination pilot projects, which gave individuals with developmental disabilities authentic person-centered planning, choice and control over their services and supports, and better outcomes, with potential long-term cost savings. The legislation required California to seek federal funding for the program by the filing of a waiver application by the Department of Developmental Services (DDS), which was developed over a period of several years and submitted in March 2018. The federal government approved the waiver application on June 7, 2018, which initiated a three-year phase-in period in which 2500 interested regional center consumers were randomly selected to participate. The purpose of the phase-in period included the opportunity to implement the SDP prior to its expansion to become available to all regional center consumers on June 7, 2021.

The membership of the Statewide Self-Determination Advisory Committee (SSDAC) consists of the chairs or designees of the 21 regional centers Self-Determination Local Advisory Committees (LAC) and a statewide co-chair appointed by the State Council on Developmental Disabilities. The LACs' legislative mandate is to provide oversight and guidance on the implementation of the SDP. As of August 2020, just over 200 regional center consumers have transitioned into the SDP, of which nearly half are former participants in the 20-year-old self-determination pilot projects. The SSDAC has engaged in an exercise to identify barriers to implementation of the SDP in collaboration with regional center staff and interested/involved members of the developmental disabilities' community, and to make recommendations to overcome them.

## Summary of Findings

The SSDAC found that significant barriers to implementation of the SDP fall into the following four broad categories, which are not exhaustive:

1. Delay in implementation of the SDP.

2. Lack of guidance by DDS to regional centers and consumers, resulting in inconsistent implementation of the SDP across the regional center system.

3. Lack of trainings for regional center's staff, participants and families.

4. Lack of trainings for, and development of person-centered planners, fiscal management services, independent facilitators and service providers.

## Barrier 1: Delay in Implementation of the SDP

The excitement about an anticipated new and different means of delivery of services and supports to regional center consumers in 2013 has been tempered by a nearly five-year delay in seeking and obtaining approval of its federal waiver application. While DDS should be commended for shepherding the waiver application through a hard and complicated process, this delay has resulted in a loss of momentum for and interest in the SDP by many individuals and families. The inability to timely move the program forward has left many regional center staff, LAC members, and consumers and families with low enthusiasm for the SDP. This has become worse due to COVID-19. The loss of momentum has impacted systemic change in the philosophy, culture, attitude and practice of self-determination. In many instances, potential participants have expressed a lack of understanding of the program, fear of change, discouragement, and a lack of hope. A "paradigm shift" in which people believe that they have substantial freedom of choice and the ability to control their own lives has not yet occurred.

## Recommendations

- DDS and regional centers should provide monthly reports to LACs which include the number of SDP participants, the pace of enrollment, orientation, development of person-centered plans and budgets, and transition into the program which are broken down by regional center, race/ethnicity, and the number of previously-interested individuals and families who have disenrolled from the SDP.
- DDS should timely share the results of the survey of those who have disenrolled from the SDP to discover and understand the rationale for disenrollment with LACs and SSDAC. Once received, the SSDAC should analyze the results and make recommendations to increase participation in the SDP.
- DDS should establish a goal for participants to transition to the SDP within six-months from the date of selection.
- DDS should establish benchmarks for implementation of the SDP by regional centers. LACs should monitor progress and attainment of established goals.
- The SSDAC should share models of success and encourage LACs to apply lessons learned to local implementation.

## Barrier 2: Lack of Guidance by DDS to Regional Centers and Consumers

A common theme among members of the SSDAC is that regional centers do not have consistent SDP implementation guidelines. DDS has been slow to issue guidance and directives to regional centers and SDP participants. Despite the efforts of DDS, many participants and regional center staff have not understood the mechanics of self-determination. A lack of guidance inevitably leads to DDS having to react to emergent issues on a case-by-case basis, leading to geographic disparities in implementation. Underserved communities face additional obstacles to self-determination, and evidence exists that racial and ethnic disparities are perpetuated by the SDP. Inconsistent processes within the SDP have been developed by regional centers which are accustomed to rules, forms and procedures, and therefore have not adjusted to the new self-determination normal, in which the participants are “in charge.” While flexibility and creativity are hallmarks of self-determination, “bureaucratization” of the SDP has discouraged potential participants, leading to high drop-out rates. DDS has not provided necessary oversight over and required accountability from regional centers, some of which are proactively implementing the SDP and others which are overtly or covertly resisting its implementation. The result is an overall inconsistency of the rollout of the phase-in period.

## Recommendations

- DDS should issue clear and consistent guidance and directives to regional centers and Local Advisory Committees, including in the following areas: orientation, person-centered planning, use of generic resources, development of spending plan and budget, and trainings.
- DDS should identify and hire a “champion" within DDS dedicated to coordinating the implementation of the of SDP with regional centers.
- DDS should establish and update FAQs on its website.
- DDS and regional centers should draw on the experience of self-determination pilot projects.
- Regional centers should develop an effective means of facilitating the dissemination of DDS guidance and directives to regional center staff, whether by the establishment of “dedicated” SDP service coordinators, or through cross-training all service coordinators.
- DDS should provide a clear definition of the term, “unmet needs” for systemic application.
- Regional centers should utilize available funding for individuals’ initial person-centered planning process.
- LACs should consult with regional centers on best practices and share them with the SSDAC, which should highlight “beacons,” those regional centers which are performing well.
- DDS should monitor implementation of the SDP by regional centers for underserved participants and those with prior unmet needs in order to avoid racial and ethnic disparities.
- DDS should prioritize systemic oversight and require strict accountability of regional centers.
- The goal of DDS and regional centers should be to establish continuity across all SDP systems.

## Barrier 3: Lack of Trainings for Regional Center Staff, Participants & Families

DDS undertook an effort to introduce the principles of self-determination and the processes of the SDP in the Fall of 2018 by promoting and conducting six separate all-day orientation/training sessions throughout the State, in which regional center staff participated. While the trainings were not exhaustive, they were well-received by those who attended. However, there has been no mandate that regional center staff attend an orientation, the result of which is that many service coordinators know very little about the SDP, even though they occupy a front-line position in implementation. In some instances, service coordinators did not have an understanding that SDP participants could select an independent facilitator of their own choosing to conduct person-centered planning. Regional center staff have had difficulty understanding the budget process. Some service coordinators have stated that the SDP is only for those who have uncomplicated requirements; while others view the SDP as applicable only to those who have complicated plans and large budgets. There is no systemic consistency in the presentation of the SDP opportunity to consumers and families.

Similarly, DDS has encouraged regional centers to develop their own orientations and trainings for prospective participants. While it is a good goal to tailor the SDP to the specific constituencies within each regional center, this has led to a variety of orientation and training approaches and materials. Confusion and misunderstandings have arisen, due in some instances to a lack of plain-language, uncomplicated trainings for consumers and families. There has been inconsistency among regional centers in post-orientation follow-up of participants. This has resulted in unacceptable drop-out rates by those who had previously expressed interest in the SDP.

## Recommendations

- DDS should develop mandatory, consistent training regimens for regional center staff, and should provide timelines for and oversight of trainings and require accountability from regional centers. Trainings should include participation by LAC members. Trainings should include a focus on the spending plan and budget processes in order to avoid confusion and inconsistent communication with participants and families.
- DDS should develop required information meetings and orientations in short, plain-language format, in English and Spanish languages. Explanations of the roles of financial management service and independent facilitator should be simple and presented in plain-language format. The SSDAC should provide feedback to LACs and regional centers on best practices and training models. Orientations should include LAC members as active participants.
- Regional centers should conduct trainings and orientations at multiple times and places, including virtual presentations, in English and Spanish. Use of technology when available, combined with individual family and small-group meetings, should be initiated in order to reach all potential participants. LAC members should not only participate in orientations and trainings but should lead them. The focus of all trainings should be on purpose vs. process, including an emphasis on “who is in charge” and encouragement of individuality and creativity in the development of person-centered plans.
- Regional centers should be required to follow up with all consumers and families who have participated in orientations. LACs should invite all SDP participants to committee meetings.

## Barrier 4: Lack of Trainings for, and Development of Person-Centered Planners, Fiscal Management Services, Independent Facilitators and Service Providers

The success of the SDP is dependent upon participants' ability to locate providers who they can trust. The hallmark of the self-determination pilots was the development of networks of providers who worked seamlessly to assist participants in the development of person-centered plans, creation of budgets, management of funds, location of available services and supports, and coordination with regional center staff. Barriers have emerged during the rollout period due to participants' inability to find trained independent facilitators, a slow vendorship process for FMS', and a lack of traditional service providers who have an understanding of the opportunity to provide services and supports outside of the traditional, vendored system. There is some evidence that some vendored FMS' have elected to not participate in the SDP statewide, or have restricted the intake of participants depending upon the complexity of plans.

There are no training materials or outreach to persons interested in becoming person-centered planners and independent facilitators, resulting in inconsistencies in the development of plans. It is anticipated that as the number of participants increases, an independent facilitator "profession" will develop. However, that has not yet occurred, resulting in excessive reliance by participants on regional centers service coordinators to develop person-centered plans and budgets. The sole required vendors in the SDP are FMS'. The requirements for statewide vendorization of FMS organizations are burdensome, thereby limiting the number and variety of FMS' available to participants. In some instances, FMS' have experienced delays in timely receipt of funds from regional centers in order to pay for services and supports. Service providers who provide services and support in the traditional delivery system are unfamiliar with and lack knowledge of the SDP. This impacts the creativity and individuality of person-centered plans.

## Recommendations

- DDS should develop training materials for person-centered planners and independent facilitators. However, regional centers should not be restricted from developing additional training materials specific to the needs of their constituents. Regional centers should conduct outreach to potential person-centered planners and conduct trainings for interested persons and entities. Regional centers should provide opportunities for participants to meet and engage with independent facilitators. This should not be left to the "marketplace." As a marketplace develops, regional centers should not limit outreach to "certified" independent facilitators which could limit choice of independent facilitators by participants.
- DDS should develop a plain-language explanation of the role of the FMS. DDS should provide direct oversight of FMS' and require accountability, and should streamline the guest vendorship process for FMS' in order to increase FMS choices for participants. DDS should publish on its website accurate information about FMS' who are available to provide services in each regional center. Regional centers must timely distribute funds to FMS' so as not to delay payment to providers of services and supports, and to meet participants' immediate needs or respond to crises.
- Regional centers should inform and educate current, vendored service providers about the SDP, and should recruit non-vendored providers to offer services to SDP

participants. LACs should invite providers to attend their committee meetings in order to inform them of opportunities to provide services and supports.

## Conclusion: Achievable Outcomes

The foundation of the SDP is based on the principles of freedom, authority, support, responsibility and confirmation. Self-determination is not new. The program comes from California's successful, 20-year pilot projects. The opportunity to provide individuals with authentic and meaningful choice and control over their services and supports, and therefore their lives, will produce better outcomes and likely long-term cost savings. The SDP is in its infancy.

The purpose of the three-year phase-in period is to test processes, learn from common errors, and identify best practices and apply them systemically as the SDP goes statewide in 2021. DDS, regional centers, SSDAC, LACs, advocates, participants and families all have a role to play in the success of the program. The identification of barriers to implementation should not be construed as an indictment of self-determination or as a failure of the SDP. Instead, after a rigorous analysis of barriers, the recommendations contained in this report are intended to overcome barriers in order to achieve the objectives of the SDP. The SSDAC has concluded that in part, the small size of the SDP participants selected during the phase-in period is in itself, a barrier. It is widely expected to be overcome beginning in 2021 as the program becomes available to all regional center consumers and families who are interested in the SDP, which is a positive step forward to self-determination.

This is not complicated. The SDP structure and systems are in place. The SSDAC and its LAC members are committed to collaborating with DDS, State Council on Developmental Disabilities and regional centers to overcome the barriers to implementation in advance of June 2021 and thereafter. It is only with such collaboration; will the program achieve the results which were intended by the passage and signing of SB 468 in 2013.