Regional Center of Orange County
1525 North Tustin Avenue
Santa Ana, CA 92702

Self-Determination Program Local Advisory Committee Meeting
Monday, July 6, 2020
6:30 p.m. - 8:30 p.m.
Virtual Public Meeting

"Self-determination provides consumers and their families with an individual budget which they can use to purchase the services and supports they need to implement their Individual Program Plan (IPP)."

1.	Welcome and Introductions a. Welcome Attendees b. Introduction of the Self-Determination Program Local Advisory Committee (SDPLAC) c. Purpose of meeting and how to obtain help with personal issues	Rhys Burchill
2.	Approval of June 8, 2020 Meeting Summary	All
3.	RCOC Self-Determination Updates a. Participants b. Independent Facilitator Training c. FMS Agencies and Referrals d. RCOC's Written Disencumbrance Policy	RCOC
4.	Report on State Self Determination June 9th meeting	Karen Millender
5.	Discussion: "Top 10 Barriers to Implementation of the Self-Determination Program" Report prepared by Statewide Advisory Committee	All
6.	Cost of providing mentoring services to SDP Participants	RCOC
7.	Discussion: Committee member to share suggestion on how to use Self-Determination Funds	All
8.	Share your Self-Determination Program experience and ask Questions	Members of Public
9.	Agenda Items for the next Local Advisory Committee meeting	All
10.	Adjourn	

Report on Top 10 Barriers to Implementation of the Self-Determination Program

Prepared by the Statewide Self-Determination Advisory Committee
Consisting of the Chairs or Designees of the
21 Regional Center Local Advisory Committees
DRAFT AS OF - February 5, 2020

Overview: On October 7, 2013, Governor Jerry Brown signed Senate Bill 468, creating a statewide Self-Determination Program (SDP). It is based on a successful 20-year pilot program, which gave individuals with developmental disabilities authentic person-centered planning, choice and control over their services, and better outcomes, with potential long-term cost savings. The law required California to receive federal funding for the program and set out a deadline of December 31, 2014 by which the Department of Developmental Services (DDS) was required to submit a waiver application. DDS didn't actually submit the application until March 2018 and the federal government approved it on June 7, 2018. This started the clock ticking on a three-year phase-in period in which 2,500 interested regional center consumers would be randomly selected to participate. The selection was made based on geographic and ethnic diversity factors on October 1, 2018. Participants, however, were unable to attend a required orientation until DDS made it available in April 2019.

This significant delay had an effect. DDS reported in November a significant percentage of individuals statewide have decided not to participate in the program. In late November 2019, DDS selected additional participants to backfill those spots. But as of the end of January 2020, only 112 participants have fully entered the Self-Determination Program, approximately 80 of whom were part of the Self-Determination Pilot Project and were required to enter by September 2019.

The members of the Statewide Self-Determination Advisory Committee (SSDAC), consist of the chairs or designees of the 21 regional center local advisory committees and the statewide chair appointed by the State Council on Developmental Disabilities. The local committee's legislative mandate is to provide oversight and guidance on the SDP implementation, have significant concerns about the high drop out rate of the program before it had even begun. As primarily self-advocates and family members, we are committed to identifying and overcoming the barriers that caused this attrition before the program goes statewide in June 2021. Based on discussions at our various regional centers, we present the following recognized barriers as well as recommendations to overcome them.

THE TOP 10 BARRIERS TO THE IMPLEMENTATION OF THE SELF-DETERMINATION PROGRAM

1. Significant delay by DDS in implementation

Background: More than six years passed after the self-determination law was signed before a single participant officially started in the program. This delay – twice as long as it took California to implement the Affordable Care Act – led to a significant loss of momentum for the program and a loss of interest by many individuals and families. Some regional center executives have told some of our members that they are skeptical that the program will actually ever begin. DDS's inability to move the program forward at a reasonable pace has left many regional center staff, advisory committee members, and consumers and families with low enthusiasm for the program.

Example: DDS has stated that they would be surveying participants who have chosen not to continue in the program. Yet it is unclear if that survey has ever been sent and if we have any idea why individuals have dropped out. If DDS has sent the survey, they have not shared the results. We have heard anecdotes of individuals being discouraged to participate in the SDP by the regional center service coordinators and other staff.

Recommendations:
- DDS and regional centers should provide monthly reports on the number of participants who have officially started the Self-Determination Program, broken down by race/ethnicity
- DDS should immediately send out surveys directly to people who dropped out of the SDP instead of the regional center administering the survey to avoid any conflicts
- DDS should directly ask participants if the choice to drop out was their own to ensure there was no influence by regional centers or other professionals
- DDS should make the results of the surveys available as soon as possible to the SCDD, SSDAC, local committees, as well as regional centers and other interested parties
- The SSDAC should analyze the results of the surveys to explore barriers to participation and make recommendations to DDS and regional centers to encourage increased participation during the phase-in period.
- To make sure that there is adequate evaluation of the phase-in period, which is to be completed by SCDD, DDS should set a six-month deadline for participants to transition into the program after orientation

2. Lack of timely, comprehensive and consistent information and guidance from DDS

Background: DDS has been very slow in providing written guidance to regional centers and participants about the Self-Determination Program. In the absence of complete information, we have heard of regional centers guessing about the rules, providing significant inconsistencies among regional centers. These information vacuums have wreaked havoc for many SDP participants who are sent down the wrong path to start their programs or are given information that is just plain wrong. In addition, much of the guidance provided by DDS is sent directly to regional centers and often never makes it to participants, families, and others. Moreover, DDS does not provide regular follow up with regional centers to ensure that the guidances are being followed.

Example:
In February 2019, DDS released guidance on the ability of participants to hire an individual to assist them with person-centered planning before they enter the SDP. The brief guidance made clear that a participant could use a specific 024 service code and hire a non-vendored provider. Participants, however, found that regional centers were not following the directive and were requiring them to put out the money – as much as $2,500 – in advance and get reimbursed. This clearly discriminated against low-income participants, so DDS issued a clarifying guidance on September 3, which stated that regional centers could pay the non-vendored provider directly. Yet the regional centers continued to resist. As of today, we have heard most providers are still waiting months to be paid and some regional centers are continuing to ask for them to get vendored, which is a long bureaucratic process.

Recommendations:

- DDS needs to issue clear directives to regional centers so that there is consistent information and messaging
- Directives should also be sent directly to all members of local advisory committees
- DDS needs to update its FAQs on its website immediately, as it has promised for the past year
- DDS should be proactive with its follow up and oversight on directives instead of waiting for participants to complain
- As questions continue to be posed by participants and committees, answers from DDS should be made available to the public so that others can benefit

3. Lack of plain language, uncomplicated trainings for participants and families

Background:
DDS developed the two mandatory trainings required of participants in the phase-in: 1) the informational meeting to sign up for the random selection; and, 2) the orientation for selected participants. DDS has asked for input from the advisory committees on the two trainings and have encouraged regional centers to make the trainings their own. Self-advocates created the orientation in plain language, which was adopted by DDS. Yet confusion remains among most of the participants. Misunderstandings are particularly widespread around the development of the individual budget and spending plan. In addition, many regional centers are presenting trainings and orientations by staff only, without the participation of their local advisory committees. This misses an opportunity to use trusted self-advocate and family member peers who are part of the Self-Determination Local Advisory Committees as trainers. It poses a significant barrier to starting the program if a participant doesn't understand the fundamentals.

Example:
The law requires all participants/families to receive an orientation before entering the Self-Determination Program. DDS spent over a year developing the orientation, including input from the statewide and many local advisory committees. Yet the resulting orientation, which clocks in at over six hours, is seen as inaccessible by many. Language is often complex and very bureaucratic. Participants remain confused but mostly completely overwhelmed. Despite completing a six-hour orientation, many participants complain that they don't know what to do next.

Recommendations:
- DDS needs to revamp the orientation to make it shorter, less bureaucratic, and with more plain language, using the SSDAC for feedback
- The explanation of the roles of the Financial Management Services (FMS) are too technical and have been found to be intimidating by many participants
- Regional centers should be utilizing peer-to-peer trainers by including members of their local advisory committees in presenting trainings and orientations to increase trust and ensure plain language
- DDS should address the specific areas where participants have expressed particular confusion, including the development of individual budget and spending plan, the differences between the Person-Centered Plan (PCP) and the Individual Program Plan (IPP), and the roles of the FMS, service coordinator, versus independent facilitator
- Regional centers should offer trainings and orientations at multiple times and various days and hours

- The orientations should be more individualized, with opportunities to work one-on-one with participants
- Local advisory committees should set up support groups for participants and families to exchange information
- A handbook, accessible manual, or start-up guide should be created and given to all new participants
- Local advisory committees should develop role models from among the participants to show how the SDP can works and mentor others

4. Lack of mandatory comprehensive training of regional center staff

Background:
While participants or their families are required to go to a six-hour orientation, no such mandate exists for regional center staff. In fact, the training of managers and service coordinators who work directly in the SDP is profoundly lacking. Participants are reporting that their service coordinators know very little about the program and have given them incorrect information. Others state that they were persuaded to use their service coordinators to conduct their person-centered plans and didn't understand the option to hire a person of their choosing. The lack of staff training is having the greatest effect on the development of the individual budgets and the exploration of unmet needs.

Example:
A participant reported that he went to a meeting at his regional center, which he thought would just be an introduction to the Self-Determination Program. When he arrived, his service coordinator, whom he was meeting for the first time, told him that the meeting would be his person-centered plan. He was not prepared to direct his plan that day, had not invited his circle of support, and had not set the agenda, but he felt compelled to participate. A few months later, he conducted an authentic person-centered planning meeting surrounded by family, friends, and supporters. His service coordinator, who also attended, felt the meeting "was about the same" as the one she led.

Recommendations:
- DDS should develop a mandatory consistent training for regional center staff
- DDS should set up technical assistance teams for each regional center, including experienced DDS personnel and regional center staff mentors
- Training should focus on the giant paradigm shift that the person with the disability is in charge of their life
- DDS should define what a service coordinator does in the SDP
- Members of the local advisory committees should participate in the development and leading of the trainings

- Service coordinators from all regional centers should be able to connect and exchange ideas
- Service coordinators should attend the local advisory committee meetings

5. <u>Bureaucratization of program</u>

Background:
Individuals and families have been interested in the Self-Determination Program partly because they wanted to avoid the bureaucratic processes and limited choices of the traditional system. But as the SDP has rolled out, bureaucracy still seeps through. Because the implementation is being managed by a state bureaucracy and large regional center agencies who are accustomed to rules, forms, and codes, they seem unable to adjust to a new normal and can't help but make things more complicated than they need to be. Thus, the processes within the SDP are overly burdensome, or at least appear that way to many of the participants. Individuals are expected to jump through so many hoops that many are abandoning the program because, as many say, "it's just not worth the hassle." Independent facilitators and FMSs are reporting similar barriers.

Example:
The development of a participant's individual budget is critical, as it must take unmet needs and changes in circumstances into account. DDS developed a "budget tool" that regional centers can use with their SDP participants to help identify unmet needs. Unfortunately, the tool is so complicated that most regional centers are finding it very difficult to use. While DDS is currently working on a more simplified version, there are many participants currently moving through the process who will not benefit from it.

Recommendations:
- DDS and regional centers should use the local advisory committees as a sounding board for all directives and tools. Using plain language and simplified ideas will benefit regional centers as well as participants
- DDS should turn to the pilot participants for advice on how the program can work in a more simplified way without rules and processes.
- DDS needs to streamline the process of criminal background checks for support staff, which can take many weeks

6. Inability to find trained initial person-centered planners, financial management services (FMS), independent facilitators (IF), and service providers

Background:
A key to a successful Self-Determination Program is for a participant to find providers that they trust. As the SDP rolls out, participants have found few trained independent facilitators, a slow vendorship process for FMSs, and a small amount of traditional service providers choosing to serve SDP participants. Specifically for independent facilitators, the challenge has been that many participants and others have clamored for a list of providers. Some agencies and organizations have developed such lists, but it then mirrors the traditional system where people think they must select a provider from a list. There also needs to be more training for independent facilitators, particularly for those who will work with underserved communities. In addition, traditional service providers have generally been uninterested in the SDP. Perhaps it is because of the small number of participants during the phase-in or their lack of knowledge of the program, but it is critical that these experienced providers engage in the SDP. Particular attention should be paid to those with high medical or behavioral support needs, who require specialized service providers who often cost more and are harder to find.

Example:
DDS was extremely delayed in releasing guidance to regional centers on how to vendor FMS agencies. But they made it clear that if a FMS is vendored in one regional center, the process to become vendored in another should be streamlined and not complicated. Unfortunately, the reality has been quite different. As participants were getting ready to begin the SDP, some were finding that not a single FMS was vendored at their regional center. Others were finding that only one or two were available, despite eight being vendored statewide. FMSs are still facing overly bureaucratic vendoring processes at some regional centers, including filling out 20-page packets for a “guest vendorship,” which should have been unnecessary. The Self-Determination Law requires a “choice,” but that is not currently happening at many regional centers.

Recommendations:

- While lists of IFs should be discouraged, regional centers and local advisory committees could provide many opportunities for participants to meet prospective facilitators through meetings, fairs, and list serves
- Trainings for independent facilitators should be encouraged. Local advisory committees should coordinate networking groups for IFs. Participants should be encouraged to select people who know them well to get training and enroll as an IF.

- The DDS website currently lists all eight FMSs being available at every regional center, even though this is not true. The website should reflect only those FMSs that have been vendored at each regional center
- DDS should clarify and provide oversight about the FMS guest vendorship process to ensure it is simple and streamlined, thus providing choice for participants
- DDS should issue a directive explaining the role of the FMS and that the participants are in charge
- DDS should provide advance payments to FMS providers to ensure that participants have the ability to respond to immediate needs or crises
- Current vendored service providers need to be educated about the SDP, perhaps through the regional centers' vendor advisory committees

7. Concern that racial and ethnic disparities will be perpetuated in the SDP

Background: California's legislature has long recognized the significant racial and ethnic disparities in the amount of services that individuals receive through their regional centers. Purchase of service data reveal that people of color receive 1/3 to 1/2 of services that whites receive, with Latinos facing the greatest disparities. Since a participant's individual budget is based on their previous expenses, these underserved communities are walking into the SDP at a great disadvantage. They face an uphill battle just to have the same opportunities as whites and will be required to make a case for unmet need. Since the selection of the initial phase-in participants was based on ethnic diversity, there are significant numbers of individuals facing this challenge.

Example:
Some Latino parents are reporting that they are intimidated by the process and orientation. Many seem unknowledgeable about the basic tenets of self-determination, despite attending the orientation. Some lack trust in their regional centers, which makes getting their support even harder. While it is unclear how many underserved people of color have started the SDP because no data has been provided, anecdotally it appears that very few have begun.

Recommendations:

- DDS needs to put out directives, training materials, and participant information and notices in different languages. DDS needs to formally translate the FAQs at least into Spanish, which now is only available using Google Translate
- DDS needs to provide additional oversight of regional centers when looking at the budgets and participation of underserved individuals

- Special attention needs to be paid to the participants who are children, many of whom have no or extremely low budgets, making it impossible for the SDP to work
- DDS and the SSDAC should be analyzing participation and budget amounts by race and ethnicity. Where there are clear trends that disparities are being perpetuated, DDS should get involved deeply in that regional center to provide technical assistance
- Local advisory committees should be encouraging participants facing disparities to come to meetings and should reach out to them individually for support, if necessary

8. <u>The Self-Determination Program is being implemented inconsistently across regional centers</u>

Background:
It is well known that certain regional centers are more generous with services than others. This inequality plays out in a similar way in the SDP, as some regional centers are working to address unmet needs more aggressively than others. These "geographic disparities" cannot continue to play out in the SDP or the program will not prove successful for the many individuals with extremely low budgets. Part of the problem exists because of lack of staff training. But much of the issue is caused by policies or practices at certain regional centers that provide very few services.

Example:
Just listening to the local committee reports at our SSDAC meetings displays the dramatic differences in the ways that the SDP is being implemented among regional centers. Some centers are embracing their local committees and co-sponsoring fairs and trainings. Others are trying to control the program and are making it more bureaucratic than necessary. Some are ensuring that unmet needs are incorporated for underserved individuals. Others are incorrectly interpreting the budget development process in a highly restrictive way.

Recommendations:

- Consistent mandatory training of executive staff and service coordinators will help to reduce geographic disparities
- DDS should increase oversight and proactive technical assistance of regional centers
- DDS should provide data to the SSDAC regarding the status of participants at each regional center
- The SSDAC should establish benchmarks for implementation and monitor them at each regional center

9. Lack of effective oversight and accountability

Background:

DDS has been primarily reactive in its approach to concerns that arise in the implementation of the SDP. As an individual problem arises and DDS is alerted by a participant or independent facilitator, they provide technical assistance. This usually consists of an email or call explaining an issue but sometimes has involved reaching out to a regional center. But as DDS puts out one fire, another arises. It is critical that DDS be more proactive and look at systemic issues across the state. Waiting till a problem occurs and then reacting puts participants and families in difficult situations leading to increased drop out rates. In addition, there are other levels of oversight besides DDS, including Disability Rights California and their Office of Clients Rights Advocates who sit on every local committee, which has met inconsistently and has not functioned well over the last almost four years. SCDD has the responsibility to survey SDP participants' satisfaction and report to the Legislature on the implementation of the SDP by June 2021, but with an unknown number of people in the program it is almost impossible to evaluate. The Office of Administrative Hearings, who will rule on fair hearings related to the SDP, has received no training on the SDP, and anecdotally we are hearing that Administrative Law Judges know nothing about it. Finally, the state legislature has ultimate oversight and could be much more engaged.

Example:

A participant was having a major problem moving forward with their self-determination program. They contacted DDS for assistance and was provided with some information. That participant shared that information with their regional center but it was not followed. The participant had to reach out again to DDS and ask for more help, and DDS contacted the regional center to resolve the issue. Meanwhile, many months go by and the participant hasn't entered the program. And we know that many other participants are having the same problem but don't know to contact DDS, or are afraid to ask for help.

Recommendations:

- DDS needs to prioritize systemic oversight as opposed to addressing only individual issues
- DDS should make available the types of questions they are asked and the answers they have provided so that others can benefit
- DDS's new staff hired through an increased $8.1 million appropriation in the 19-20 budget that includes regional center liaisons should be trained on the SDP and provide on-sight technical assistance and trainings to regional centers

- Clients' Rights Advocates should be better trained on the SDP, play a more active role on local committees, and support participants and appropriate implementation
- Administrative Law Judges need training on the SDP as soon as possible and Disability Rights California and the SSDAC may want to be involved
- Members of the SSDAC need to take a greater leadership role in providing oversight and identifying systemic barriers. The committee should meet more often, communicate more seamlessly with DDS, and gather information from participants regularly

10. Shift in culture and thinking has not yet occurred

Background:
Self-determination is a massive paradigm shift for everyone in the system. Individuals with disabilities and families, who are accustomed to accepting limited choices and being guided by "experts," need to be comfortable with taking charge of their lives and services. Regional center staff must shift to the understanding that the participants are in charge of their lives. This means they need to be more comfortable being "hands off" with the individual's choices and allow them the "dignity of risk" to make mistakes like people without disabilities do. This transition will be difficult and will take time, but we need to be diligent and monitor the situation locally to ensure that all are in alignment with the principles of self-determination: freedom, authority, support, responsibility, and confirmation.

Example:
A participant reported that he is having a difficult time getting started in the program and is facing concerns about developing his budget. As he advocated for a budget that addresses his unmet needs, he received an email from his service coordinator questioning whether the Self-Determination Program is right for him. We have heard this scenario with others and know of situations where participants have dropped out because they were convinced that the program couldn't work for them.

Recommendations:
- SSDAC should form a network of participants to share models of success
- Regional center staff who have already made the shift to the new paradigm should be identified as mentors and trainers for other regional centers
- At every step, we should be asking, "Who is in charge?" If it's not the participant, then something is wrong
- We need to figure out a way to "sell" this new paradigm to regional center staff and traditional service providers
- Participants and families need to be supported in their new role, checking in with them regularly