



NOTICE/AGENDA

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STATE COUNCIL ON DEVELOPMENTAL DISABILITIES
Statewide Self-Determination Advisory Committee Meeting

POSTED AT: www.scdd.ca.gov

DATE: February 10, 2020

TIME: 10:30 A.M. – 4:30 P.M.

MEETING LOCATION:

Hilton Sacramento Arden-West
 2200 Harvard Street
 Sacramento, CA 95815

COMMITTEE CHAIR:

Maria Marquez

Item 1.	CALL TO ORDER	
Item 2.	ESTABLISH QUORUM	
Item 3.	WELCOME AND INTRODUCTIONS	Page 3
Item 4.	RECAP OF PREVIOUSLY ESTABLISHED GROUND RULES All	Page 4
Item 5.	APPROVAL OF OCTOBER 2019 MINUTES 	Page 5
Item 6.	CO-CHAIR ELECTION  Presented by: Maria Marquez, Chair	Page 15
Item 7.	DDS UPDATE ON SELF-DETERMINATION PROGRAM Presented by: DDS	Page 19

		
	LUNCH	
Item 8.	TOP 5 BARRIERS  Identify recommendations to address top 5 barriers and identify who is responsible for addressing them. All	Page 22
Item 9.	MEETING FREQUENCY AND FUTURE AGENDA ITEMS  All	Page 34
Item 10.	PUBLIC COMMENTS This item is for members of the public only to provide comments and/or present information to the Committee on matters not on the agenda. Each person will be afforded up to three minutes to speak. Written requests, if any, will be considered first.	
Item 11.	ADJOURN	

Accessibility:

Pursuant to Government Code Sections 11123.1 and 11125(f), individuals with disabilities who require accessible alternative formats of the agenda and related meeting materials and/or auxiliary aids/services to participate in this meeting should contact (916) 322-8481. Requests must be received by 5 business days prior to the meeting.

Materials:

Meeting documents and presentations for an agenda item must be submitted to SCDD no later than 2 business days prior to the meeting.

All times indicated and the order of business are approximate and subject to change.

A call-in phone line will be available so that members of the public can call in and listen to this meeting, provided there are no unforeseen technical difficulties or other limitations. The meeting will not be cancelled if the call-in phone line is not available. If you wish to participate or to have a guaranteed opportunity to observe and participate, please plan to attend at a physical location.

February 10, 2020

**AGENDA ITEM 3.
INFORMATIONAL ITEM**

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES – SSDAC

Welcome and Introductions

Committee members and others present will introduce themselves.

In October 2019, the SCDD Executive Committee reconsidered SSDAC's previous request to establish a Coordinating Committee. After hearing public comments, the Executive Committee determined that the SSDAC has a unique statutory structure and recognized the need for SSDAC to be more autonomous.

Therefore, the SSDAC Chair, Council Vice-Chair, along with a small number of SSDAC members and DRC formed a workgroup that met in December to discuss how to operationalize this. The workgroup meeting covered the process for selecting a co-chair, setting future SSDAC agendas, meeting facilitation, workplans, and more. Today's agenda, along with many of the materials, reflects the outcomes reached at that meeting.

February 10, 2020

**AGENDA ITEM 4.
INFORMATIONAL ITEM**

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES – SSDAC

Recap of Previously Established Ground Rules

In June 2019, the Statewide Self-Determination Advisory Committee agreed these ground rules to help facilitate their meetings.

- ✓ **Be Respectful**
- ✓ **Work Together**
- ✓ **Participate**
- ✓ **Don't Interrupt**
- ✓ **Listen to What Others Have to Say**

February 10, 2020

AGENDA ITEM 5.

ACTION ITEM

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES – SSDAC

Approval of October 2019 Minutes

The goal of this agenda items is to review and approve the meeting minutes from the last meeting.

Action Recommended

Approve the October 2019 minutes.

Attachment(s)

October 18, 2019 Minutes



DRAFT

**Statewide Self-Determination Advisory Committee
Meeting Minutes
October 18, 2019**

Attending Members

Maria Marquez (Chair)
Tim Jin (RCOC)
Joyce Clark (SDRC)
Lisa Cooley (ACRC)
Jennifer Bowman (FNRC)
Michelle Heid (NLACRC)
David Forderer (SARC)
Irene Litherland (RCEB)
Sherry Johnson (SCLARC)
Sonia Jones (NBRC)
Rosalinda Garcia (HRC)
Mariela Ramos (VMRC)
Louise Mackenzie (TCRC)
Judy Mark (WRC)
Sascha Bittner (GGRC)
Virgilio Orlina (ELARC)
Maia Pawoskar (IRC)
Ameen Ali (SGPRC)
Pierre Landry (FDLRC)
Rick Wood (KRC)

Absent Members

Robert Taylor (RCRC)
Michelle Smith (CVRC)

Others Attending

Aaron Carruthers
Adam Lewis
Beth Hurn
Breeanne Burris
Connie Lapin
Danielle Isola
Debbie Hieden
Dena Hernandez
Elisa Escareno
Jamie Noll
Jana Chapman-Plon
Janelle Lewis
Joseph Hernandez
Laura Larson
Mary Ellen Stives
Nicole Patterson
Robin Maitino
Sahira Arroyos
Sarah May
Sonia Bingaman
Wendy Keedy

1. CALL TO ORDER

Chairperson Maria Marquez (SA) called the meeting to order at 10:42 A.M.

2. ESTABLISH QUORUM

A quorum was established.

3. **WELCOME/INTRODUCTIONS**

Members and others introduced themselves as indicated. During introductions, some Committee members as well as members of the public, sought clarification on agenda items, SCDD's role, DDS' role, and things of that nature. Chair Marquez addressed the questions to the best of her ability.

4. **APPROVAL OF THE JUNE 2019 MEETING MINUTES**

It was moved/seconded (Cooley/Orlina) and carried to approve the June 2019 meeting minutes as presented. (Abstain: Mackenzie, Mark, Heid, all other members present at time of vote, voted in favor [see page 1 for a list of voting members]).

5. **CHAIR REPORT**

Chair Marquez provided members with her report which highlighted Committee achievements dating back to 2016. Upon conclusion, several members questioned Chair Marquez stating that the Committee should be doing more.

6. **UPDATE ON SSDAC GOALS**

Chair Marquez provided the following update on the goals that were identified and adopted by the Committee at the June 2019 meeting.

Goal 1: Establish a Coordinating Committee

Chair Marquez reported that on June 18th, the Executive turned down the Committee's recommendation to establish a Coordinating/ Sub-Committee. Chair Marquez stated that since that time, the Council has received a request to reconsider SSDAC's recommendation so she has directed staff to place this item on the upcoming October 29th Executive Committee agenda for reconsideration.

Members discussed this item at length and reiterated how important they felt this goal was and wanted to make sure that they were appropriately represented at the October 29th Executive Committee.

Goal 2: PCP Implementation

Chair Marquez reported that service code 024 has been released as well as guidance on PCP funding since the last meeting. Chair Marquez also reported that she has started collecting data as requested in Goal 3 via

the report we sent to members on September 12th. Please see the attached data report for information reported.

Members felt more support and guidance was needed and that a lot of misinformation was being provided by some regional centers.

Goal 3: Communication/Forum/Framework

Chair Marquez reported that staff had drafted format to collect data from the local SDACs and sent that out to members on September 12th. Staff took then information reported and compiled it into the attached data report. Chair Marquez further stated that the format of the report was a draft and that feedback and input encouraged.

Member response to this update ranged from good to bad. Some appreciated having some data, while others felt the data was not accurate and refused to use the reporting tool since Committee members did not design it.

Goal 4: Local Advisory Committee Vacancies

Chair Marquez reported that the next Membership Committee meeting was tentatively scheduled for November 12th and that SCDD had begun the practice of placing qualified local SDAC candidates on standby should a vacancy arise in order to reduce appointment wait times.

Goal 5: SDP Implementation

Chair Marquez provided brief highlights of the overall progress made on the implementation of the Self-Determination Program, which included released guidance documents, feedback on materials and tools and more. Chair Marquez also handed out the most recent participant counts available. This document showed the total number of participant spaces available at each regional center, the number of selected individuals continuing at each regional center, and the number of open slots at each regional center.

Overall feedback from members was negative. In general, there is a feeling that DDS is not doing enough and this Committee should be doing more.

7. **BREAK-OUT GROUPS**

Committee members broke into five (5) small groups, four (4) made up of Committee members, and one (1) made up of public members. Judy Mark, Maia Pawoskar, Pierre Landry and Rick Wood led the four-member group discussions and public member Janelle Lewis facilitated the discussion for members of the public.

Each group was provided a copy of the data reported by members that responded to the email staff sent out and were free to discuss barriers, suggested recommendations, or any other items related to the program.

8. **NEXT STEPS**

Members reconvened and reported several barriers, including a lack of clarity from DDS, lack of training to regional center staff, lack of accessible materials, lack of independent facilitators, unclear training materials and much more. Members requested that SCDD staff transcribe the groups notes for future use.

Members also wanted reassured that substantive emails from SCDD, such as agendas, program updates, etc., be sent to all local members and not just the chairs. Committee member Judy Mark requested that chairs send local membership updates to SCDD staff in order to ensure accurate distribution.

9. **PUBLIC COMMENT**

Connie Lapin provided public comments stating that she would like the Committee to meet more often, that she is concerned about the drop offs and fears self-determination is going to fail.

Judy Mark introduced her DVU website forum and invited everyone to check it out, staying its very interactive and user friendly.

10. **ADJOURN**

The meeting was adjourned at 4:47 PM.

TRANSCRIBED SSDAC BREAKOUT NOTES OCTOBER 2019

GROUP 1 – Mai Poowskar

BARRIER	Recommendations
Lack of clarity from DDS Lack of policy/rules/guidelines Not enough IF/providers Mental Health Improved documentation/knowledge Not clear what is unmet need base What is additional service/support Still confusion between DDS and SCDD will support/provide FMS Lack of follow-up/support to participant after orientation Vendors are not informed/educated in self-determination CSCs need training in PCP process/approval Approval of spending plan (budget) DDS needs to provide uniform training to all regional centers on budget. New participant questions are not being answered High drop-out Need self-determination training to vendor advisory committee Need a liaison between vendor>regional center>DDS (S-D) Need training to program (consumer) instructors /agencies	A dedicated, trained team at each regional center to provide support to phase-in participant/families Self-determination technical support team BUDGET – DDS needs to provide training to all regional centers on all matters related to budget Technical Support – TA team for determination. A dedicated well trained team be an available at each regional center to answer SD questions. Provide support and follow through to phase in participants Liaison between vendor, RC, and SDAC FMS oversight

GROUP 2 – Rick Wood

BARRIER	Recommendations
Lack of consistent information re: SD implementation	DDS to issue firm directives to RCs so that RCs will be providing consistent information to consumers and families
Lack of qualified independent facilitators (IF)	RCs/local advisory committees to schedule IF trainings regularly; outreach to the

	community to encourage enrollment in trainings; fallback/default are RC service coordinators (who must be trained and dedicated to SD)
Person Centered Plans: lack of knowledge/ to develop plans; no “professionals” available	RCs to provide certified trainers to train IFs; require cultural/language diversity DDS to issue “sample” plans; RC service coordinators to be trained
Budget: Consumers fear “cap” on spending; if plan requires budget changes, who will pay for IF assistance? Confusion/delay in RC processing requests for payment for services	Unmet needs to be addressed which will increase budget; RC service coordinators to assist in changes at no additional cost; RCs need to be timely responsive to requests for payment
Financial Management Service (FMS): lack of timely payment for payroll and other services and supports; FMS control over allowable expenses included in approved plans whose budgets have been certified.	DDS to consider advance payments to FMS; DDS to issue directive to FMS to prohibit FMS interference in approved plans

GROUP 3 – Pierre Landry

BARRIER	POSSIBLE ACTION
<p><u>PCP</u> Qualified PCPs Lack of understanding PCP PCP < > IPP Intimidated Over complicated Lack of RC understanding by SCs (solution: recruit experts in PCP; multiple opps for training; individualizing; self-advocate presented training for RC staff training S/D for any services; targeted trainings for PCP, spending plan, budget, FMS, manuals and quick guides)</p> <p><u>FMS</u> Only one agency in my territory Change (triangle symbol) in nursing services FMS authority about hiring (solution: change regs)</p>	

<p>Id'd nursing skills/care services (not allowed under co-employer) I/DD with medical needs or end of life Simplify explanation of different models FMS not getting money from DDS (solution: survey FMS) FMS doesn't understand SDP, especially different models</p> <p><u>General Issues</u> Service coordinator' role definition Unclear guidelines/criteria for Ifs (no money to do certifications) Need clarity on how/why SCDD holds SSDAC Lack of skilled service providers (rates) No stats for direct services (job coaches, SLS, ILS, etc.) Delays in background check (3 mo – S/D 1 mo) After orientation, what's next General population pool (lots of non-Ps)</p> <p><u>IF</u> No list Clarity of parent Ifs, service coordinator, silos</p>	
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GROUP 4 – Judy Mark

BARRIER	POSSIBLE ACTION
Cant find IF or PCP provider	Discourage lists Encourage SD fairs, forums, list serves Inform participant to select people who know them best to then get the training
People don't know what to do next. <ul style="list-style-type: none"> - Delay - Lost momentum (D)	Support groups for participants and families Need to get more info to them Handbook Direct contact with participant without regional center filter Create role models from community Deadline to be in six months after orientation
Transition peoples thinking (C)	Live life like people without disability Form network of participants to share models of success.

	Also share with SCS. Committees share
SCS aren't will trained	LAC have training modules Need to her same thing Need models of what to do <ul style="list-style-type: none"> - Peer who has had success - Needed consistency
Information not accessible <ul style="list-style-type: none"> - Language (e.g., Spanish) - Plain language - Online 	DDS translate directives (at least to Spanish) SSDAC could vet the DDS language. Assist in making more plain.
DDS is reactive not proactive. (waits till problem occurs and then reacts too late) (B)	SSDAC can't always rely on them. We need to be more proactive. SSDAC meets more. Have easier way to get issues to DDS. Don't get involved 1 by 1. Look at systemic issues. Piecemeal.
Regional center not in alignment or supportive or SDP PCP needs to be authentic. Biggest barrier but hardest to solve. (A)	More DDS oversight Needed to "sell" this to RX staff more Participants and families don't rely on regional center Need participants to understand Better regional center training
FMS <ul style="list-style-type: none"> - People aren't at the point. - Scared - Regional centers intimidating - Ridiculous rules by FMS for selection of staff 	More strict control over FMS to understand what they can make decision on. More info to participants
Budgets to low, especially for children. <ul style="list-style-type: none"> - How to afford FMS (E. unmet need generally)	
Racial disparities	More training on unmet needs. SSDAC reviews of budgets by race LACs have meetings with participants with disparities.
Geographic disparities	Unmet needs on statewide basis. Look at data of individual budgets by age, disability, race, gender
Less bureaucratic different orientation	

GROUP 5 – Public Input

BARRIER	POSSIBLE Solutions
<p><u>Beginning (delay)</u> Delay, misinformation, no information Disparity among regional centers Service coordinators not up to date</p> <p><u>Training (delay)</u> Order of events Quality PCP IF</p>	<p><u>Beginning</u> Step by step training materials in plain language Uniform information continuously distributed in multiple languages and available online Flow charts, check lists</p> <p><u>Training</u> Ongoing Quality PCP trainings Ongoing producing plans Encourage IFs Ongoing trainings</p>
<p><u>Infrastructure (delay)</u> No providers, how to find FMS Differences across regional centers Budget – many issues clarified/simplified Ongoing relationships matter</p>	<p>need complete list of vendors and other local providers with knowledge (that not vetted?) possibility for sole employer encourage involvement in program encourage providers LAC chairs have leadership authority with State advisory committee</p>
<p>Transparency</p>	<p>Make it simple no over bureaucratic requirements Culture/paradigm shift for all agencies/families/self-advocate “Who is in charge” (important to/important for)</p>
<p><u>Questions</u> Can IHSS provider be IF? How will overtime work? Conservatorship? FMS & DDS resolved criminal background checks? What will come of this and when? (who will do it, how will we know I is done, what happens if it is not done?)</p>	

February 10, 2020

AGENDA ITEM 6.

ACTION ITEM

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES – SSDAC

Co-Chair Election

Background

On December 9, 2019, a small number of SSDAC members, along with staff and members of DRC and the State Council met to discuss ways to make SSDAC meetings more productive and assist the Chair and staff in creating agendas as well as other items requiring action. To address this, it was the consensus of the group that a Co-Chair to the Committee be established. All SSDAC members received the opportunity to submit a candidate statement. Attached are the Candidate Statements received.

Duties and Responsibilities

The Co-Chair will serve in partnership with the SCDD appointed Chair as a co-equal. Together, the Chair and Co-Chair will run SSDAC meetings, set meeting agendas and work closely together. Chair and Co-Chair will work with staff on SSDAC needs.

The SSDAC Co-Chair must be a member of SSDAC and remain a member of SSDAC to continue to serve as Co-Chair. The Co-Chair is elected by SSDAC Members through a public vote. SSDAC Co-Chair candidates can self-nominate and candidates may provide a statement answering the questions located on the following page. A SSDAC member may serve as Co-Chair for 2 years. That person may serve one additional 2-year term. No person may serve more than 4 years as the SSDAC Co-Chair.

Voting

Should this body choose, the co-chair may be elected by a simple majority vote. If no nominee is elected by a majority vote, the Committee may elect to hold a run-off election between the nominees who received the two highest number of votes.

Attachments – in alphabetical order

Candidate Instructions

Sasha Bittner – Candidate Statement

Rick Wood – Candidate Statement



2020 SSDAC Co-Chair Candidate Statement Form

Instructions

The following Candidate Statement Form is being provided to those who may be interested in nominating themselves as Co-Chair of the Statewide Self-Determination Advisory Committee (SSDAC). Candidate's must be present to be considered. Candidate statements are due by February 3, 2020 in order to allow sufficient time for Members to review Candidate's statements and may be emailed to robin.maitino@scdd.ca.gov.

Background

On December 9, 2019, a small number of SSDAC members, along with staff and members of DRC and the State Council met to discuss ways to make SSDAC meetings more productive and assist the Chair and staff in creating agendas as well as other items requiring action. To address this, it was the consensus of the group that a Co-Chair to the Committee be established. Elections for this newly created position will be voted on in February.

Duties and Requirements

The Co-Chair will serve in partnership with the SCDD appointed Chair as a co-equal. Together, the Chair and Co-Chair will run SSDAC meetings, set meeting agendas and work closely together. Chair and Co-Chair will work with staff on SSDAC needs.

The SSDAC Co-Chair must be a member of SSDAC and remain a member of SSDAC to continue to serve as Co-Chair.

The Co-Chair is elected by SSDAC Members through a public vote. SSDAC Co-Chair candidates can self-nominate and candidates may provide a statement answering the questions located on the following page.

A SSDAC member may serve as Co-Chair for 2 years. That person may serve one additional 2-year term. No person may serve more than 4 years as the SSDAC Co-Chair.



2020 SSDAC Co-Chair Candidate Statement

Candidate Name: Rick Wood

Check box confirming you can serve in-person as co-chair.

Why do you want to serve as Co-Chair? The SD law provides that the function of the SSDAC is 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. I am a parent of a 20-year participant in the KRC SD Pilot. I have been immersed in SD issues for 20+ years. I have demonstrated a passion for making a difference in participants’ lives. Leadership is manifested by the ability to persuade others, to develop consensus as a leader among equals on the development of the SSDAC agendas, to prioritize its actions, to conduct its work more efficiently, to hold DDS and RCs accountable, and to obtain meaningful accomplishment of the functions of the SSDAC prescribed in the law. I can do this as Co-Chair.

What are your experiences in leadership and/or the Self-Determination Program and meeting facilitation skills? Parent of a KRC Pilot participant for 20+ years. Served as FMS and Independent Facilitator for 20+ years. Chairman of the KRC Pilot Liaison Committee for 20+ years. Member of DDS SD Workgroup for 6+ years participating in implementation of SD law. Chair of KRC SD LAC. Presenter at RC SD staff trainings in 2018. Established relationships with DDS, RCs, and SD stakeholders. Unmatched real-time SD knowledge and experience. Served as elected member of Mammoth Lakes Town Council for 12 years, including 6 years as Mayor. Hallmark of service has been ability to develop consensus among disparate interests. Navigated politics of progressive agendas. Developed agendas and conducted/facilitate thousands of public meetings. Have capacity and experience to manage the pace of meetings, to accomplish meeting and group objectives, to provide all members with a voice in discussions, to work with the SSDAC Co-Chair.

What is your time availability to serve as Co-Chair? I am an attorney in private practice for 40+ years. I have flexibility in my schedule to attend meetings, confer with SCDD Executive Director and staff, develop agendas, implement directives, prepare for meetings, and communicate with other SSDAC members and Co-Chair. Most importantly, I have the support and encouragement of my spouse in this endeavor, which will have lasting impact on the lives of thousands of people.

2020 SSDAC Co-Chair Candidate Statement

Candidate Name: Sascha Bittner

Check box confirming you can serve in-person as co-chair.

Why do you want to serve as Co-Chair? Lack of supported living resources during my transition to adulthood profoundly affected my options for self-determination, but I was lucky to have a family committed to helping me develop a self-directed, inclusive life even without institutional support. SDP can be a real game changer for my community, and I want to make sure it works as effectively as possible for all participants, so no one has to rely, as I did, on luck. My own history with self-direction, my extensive experience with and knowledge of the system, my political networking history and my effective interpersonal skills provide a very strong combination of attributes for this position. With an inclusive, collaborative leadership style (no “silo-ing” or pitting one group against another), I can bring people together to reach our mutual goals, and I can also access lawmakers and help influence legislation if/when needed.

What are your experiences in leadership and/or the Self-Determination Program and meeting facilitation skills?

--Current Co-Chair, GGRG Self Determination Local Advisory Committee: I facilitate meetings (with a voice interpreter), partner with my co-chair, and collaborate with members, staff and other stakeholders to create trainings, troubleshoot issues and oversee program’s progression. I ask tough questions (as needed), persisting until I get satisfactory answers.

--Participant, SDP: As a new participant, I bring a fresh perspective.

--Current Chair, Bay Area Regional Advisory Committee on DD: I facilitate meetings (with a voice interpreter), advocate to legislators, etc..

--Current Speaker Nancy Pelosi-appointed CA Democratic delegate, CA Dem Legislative Committee and Disability Caucus member: I know many CA policymakers and/or staff members (Gov., Lt. Gov, Treasurer, Assembly and Senate members), and have extensive (successful) experience advocating for policies and even (as SCDD chair) co-sponsoring legislation.

--Chair, Vice-Chair & Chair Emeritus, SCDD (2004-2008): I facilitated (voice interpreter) statewide meetings of Area Board (now RAC) reps, state govt department reps and at-large members (about 30 members total). Meetings evolved from contentious, often unproductive gatherings, to ones that respectfully and effectively focused on needs of consumers and families.

What is your time availability to serve as Co-Chair? Very available. I can travel to Sacramento (or elsewhere) or communicate by phone, email, Skype, etc

February 10, 2020

**AGENDA ITEM 7.
INFORMATIONAL ITEM**

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES – SSDAC

DDS Update on Self-Determination Program

DDS has been invited to come provide an update on the status of the program. Specifically, how many names have been pulled, of those, how many have fully started, how many have dropped out and of those that have fully started, how many were in the pilot.

In addition to the general update, the SSDAC workgroup prepared the attached questions for DDS. These questions are a result of the work the SSDAC members did in their breakout session in October 2019. The SSDAC workgroup went through all the transcribed notes and synthesized their findings, wrote a report, and came up with the questions.

Attachments

February 2020, SSDAC Questions to DDS

Questions for DDS at February 10, 2020 SSDAC Meeting

- When will DDS report on the number of participants who have officially started the Self-Determination Program, broken down by race/ethnicity?
- To ensure accurate answers, when will DDS send out surveys directly to the participants?
- Is DDS going to directly ask participants if the choice to drop out was their own to ensure there was no influence by regional centers, family members, or other professionals?
- When will DDS make the results of the surveys available to the Statewide Self-Determination Advisory Committee, local committees, as well as regional centers and other interested parties?
- What is the deadline for participants to fully transition into the program after the orientation?
- When is DDS going to update its FAQs on its website? Will you be translating it into Spanish?
- How is DDS responding to those Regional Centers who are not following the law regarding SDP, including telling participants their services need to be vendorized?
- How often does DDS plan to update its website in response to questions from participants and committees, so that the public can know as well?
- What is DDS doing to make the orientation easy for everyone to understand? Is there anything SSDAC can do to help with this?
- Has DDS looked at ways to have modules on topics that are difficult for participants to understand like the different forms of FMS and IFs? Can SSDAC help with this?
- Has DDS developed a mandatory training for RC staff? Is this in the works?
- Has DDS reached out to FMS providers to make sure they understand their role?
- How is DDS streamlining background checks for support staff, so it takes weeks, not months?
- Is DDS planning to use the local advisory committees and the SSDAC as a sounding board for all directives and tools, so that there are simplified ideas and everything is in plain language?

- How does DDS plan to use feedback from participants to improve the SDP program?
- How will DDS clarify and provide oversight about the FMS guest vendorship process to ensure it is simple and streamlined, thus providing choice for participants?
- Can SSDAC receive data on the individual budgets How is DDS ensuring that racial and ethnic disparities aren't perpetuated in the SDP?
- How are you making sure that participants with significant medical and behavioral support needs are able to take advantage of the SDP?
- Are you preparing a training for the Office of Administrative Hearings on the SDP?

February 10, 2020

AGENDA ITEM 8.

POSSIBLE ACTION ITEM

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES – SSDAC

-TITLE CORRECTION- Top Ten Barriers

At the October 18, 2019 SSDAC meeting, members broke into several small groups and discussed program barriers as well as possible solutions. This information was then transcribed and sent to a small workgroup of Committee members who synthesized the information.

When the workgroup originally met, they discussed providing the top five barriers. However, the workgroup identified the top ten barriers. Attached is that report for the Committee's review and consideration.

Attachments

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

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 work 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. Bureaucratization of program

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. The Self-Determination Program is being implemented inconsistently across regional centers

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

February 10, 2020

**AGENDA ITEM 10.
INFORMATIONAL ITEM**

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES – SSDAC

Meeting Frequency and Call for Agenda Items

SSDAC is currently schedule to meet three (3) times in 2020. Meeting dates are: February 10th, June 9th and October 2nd.

February and October meetings are currently scheduled to take place in Sacramento and June's meeting is scheduled to take place in Orange County.

Members have requested to meet four (4) times per year and have input on which day of the week to meet. Therefore, members will be surveyed to establish their preference when booking future meetings.