



# NOTICE/AGENDA

**STATE COUNCIL ON DEVELOPMENTAL DISABILITIES  
STATEWIDE SELF-DETERMINATION ADVISORY COMMITTEE MEETING  
POSTED AT: [www.scdd.ca.gov](http://www.scdd.ca.gov)**

This is a teleconference and zoom meeting only. There is no physical location being made available to the public. Per [EXECUTIVE ORDER N-29-20](#), teleconferencing restrictions are waived during the COVID-19 pandemic. Therefore, Committee members are not required to list their remote locations and members of the public may participate telephonically or by Zoom from any location. Accessible formats of all agenda and materials can be found online at [www.scdd.ca.gov](http://www.scdd.ca.gov).

**JOIN ZOOM MEETING:** <https://bit.ly/ssdac620>  
**MEETING ID:** **950 9225 1627**  
**PASSWORD:** **763841**

Click [here](#) for instructions on using the Zoom application.

OR

**JOIN BY TELECONFERENCE: (VOICE ONLY)**

**CALL IN NUMBER:** **888 475 4499 US Toll-free**  
**MEETING ID:** **950 9225 1627**

**DATE:** June 9, 2020

**TIME:** 10:00 AM – 2:00 PM

**COMMITTEE CO-CHAIRS:** Maria Marquez and Rick Wood





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**Item 1. CALL TO ORDER**

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**Item 2. ESTABLISH QUORUM**

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<b>Item 3.</b>	<b>WELCOME AND INTRODUCTIONS</b>	Page 3
<b>Item 4.</b>	<b>PUBLIC COMMENTS</b> <i>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.</i>	Page 5
<b>Item 5.</b>	<b>APPROVAL OF FEBRUARY 2020 MINUTES</b> 	Page 6
<b>Item 6.</b>	<b>LOCAL SDAC REPORTS</b> <i>Presented by: All</i>	Page 12
<b>Item 7.</b>	<b>BREAKOUT: BARRIERS TO SELF-DETERMINATION IN THE AGE OF COVID-19</b> <i>Presented by: All</i>	Page 35
 <span style="color: red; font-weight: bold; font-size: 1.2em;">LUNCH</span> 		
<p>There will be a 30-minute lunch break following the introduction of the breakout session</p>		
<b>Item 8.</b>	<b>BREAKOUT REPORTS</b> 	Page 47
<b>Item 9.</b>	<b>NEXT MEETING</b> October 2, 2020	Page 48
<b>Item 10.</b>	<b>ADJOURNMENT</b>	

**Accessibility:**

Pursuant to Government Code Sections 11123.1 and 11125(f) and Executive Order N-29-20 (this Executive Order can be found by clicking the link on page one of the agenda or typing <https://www.gov.ca.gov/wp-content/uploads/2020/03/3.17.20-N-29-20-EO.pdf> into your web browser), 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 Robin Maitino-Erben at (916) 263-8193 or [robin.maitino@scdd.ca.gov](mailto:robin.maitino@scdd.ca.gov). Please provide at least 3 business days prior to the meeting to allow adequate time to respond to all requests.

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

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**June 9, 2020**

**AGENDA ITEM 3.  
INFORMATIONAL ITEM**

**STATE COUNCIL ON DEVELOPMENTAL DISABILITIES – SSDAC**

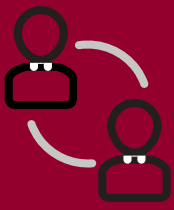
***Welcome and Introductions***

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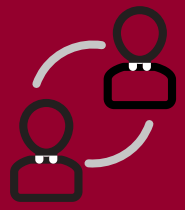
Before turning the meeting over to Committee members and others present to introduce themselves, the Co-Chairs will welcome everyone and provide a brief overview of virtual meeting etiquette.

**Attachment**

Virtual Meeting Tips



# Virtual Meeting Tips



## 1 Before the meeting

- ✓ Pick a place with little distraction
- ✓ Treat this like any in-person meeting
- ✓ Wear clothes that you would normally wear to an in-person meeting
- ✓ Light should be in front of you (not behind you)
- ✓ Close window blinds behind you

## Be on time

2



- Join the webinar a few minutes early
- Be ready to participate

## 4 Use Chat or Q&A



This keeps attendees from speaking over one another.

## MUTE until it is your turn to speak

3



- Reduce background noise.
- Listen when others are talking.

## 5 Ask to speak



When you are called on, unmute yourself, say your name, and ask your question or make your comment.

## Be Prepared

6



- Review meeting agenda and documents in advance of meeting



- Do not multi-task



- Keep on topic and stay engaged

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**June 9, 2020**

**AGENDA ITEM 4.**

**STATE COUNCIL ON DEVELOPMENTAL DISABILITIES – SSDAC**

***Public Comment***

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Members of the public will be given the opportunity to provide comments to the Committee on matters not on the agenda. Each person will be afforded up to three minutes to speak, at which time the person may be muted.

Members of the public wishing to comment on items listed on the agenda may do so prior to action being taken by the Committee.

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June 9, 2020

**AGENDA ITEM 5.**

**ACTION ITEM**

**STATE COUNCIL ON DEVELOPMENTAL DISABILITIES – SSDAC**

***Approval of February 10, 2020 Minutes***

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

***Action Recommended***

Approve the February 2020minutes.

***Attachment(s)***

February 10, 2020 Minutes



**DRAFT**

**Statewide Self-Determination Advisory Committee  
Meeting Minutes  
February 10, 2020**

**Attending Members**

Ameen Ali (SGPRC)  
David Forderer (SARC)  
Jennifer Bowman (FNRC)  
Joyce Clark (SDRC)  
Judy Mark (WRC)  
Linda Chan-Rapp (HRC)  
Lisa Cooley (ACRC)  
Maia Pawoskar (IRC)  
Mara Rupert (TCRC)  
Maria Marquez (Chair)  
Mariela Ramos (VMRC)  
Melissa Crip-Cooper (RCEB)  
Michelle Heid (NLACRC)  
Michelle Smith (CVRC)  
Pierre Landry (FDLRC)  
Rick Wood (Co-Chair, KRC)  
Sascha Bittner (GGRC)  
Sherry Johnson (SCLARC)  
Sonia Jones (NBRC)  
Tim Jin (RCOC)  
Virgilio Orlina (ELARC)

**Absent Members**

Robert Taylor (RCRC)

**Others Attending**

Aaron Carruthers  
Ashley Stampley  
Beth Hurn  
Casey Taylor  
Debby Hight  
Faviola Valencia  
Jennifer Bowman  
Jennifer Parson  
Lisa Hanlan  
Lisa Hooks  
Mary Ellen Stives  
Nicole Patterson  
Robin Maitino  
Sarah May  
Sidney Jacobsen  
Sonya Bingaman  
Stacey Martinez  
Tamica Fouts-Rachal  
Wayne Glusker

**1. CALL TO ORDER**

Chairperson Maria Marquez (SA) called the meeting to order at 10:43 A.M.

**2. ESTABLISH QUORUM**

A quorum was established.

### 3. **WELCOME/INTRODUCTIONS**

Members and others introduced themselves as indicated.

### 4. **RECAP OF PREVIOUSLY ESTABLISHED GROUND RULES**

The ground rules established at the Committee's June 2019 meeting were included in the packet as a refresher to help facilitate meetings.

### 5. **APPROVAL OF THE OCTOBER 2020 MEETING MINUTES**

It was moved/seconded (Forderer/Landry) and carried to approve the October 18, 2019 meeting minutes as amended. (Abstain: Rupert, Crip-Cooper, Chan-Rapp, all other members present at time of vote, voted in favor [see page 1 for a list of voting members]).

#### *Amendments*

Page 1 of the minutes; add Wayne Glusker as being present.

Page 5 of the minutes; correct the spelling of Maia Pawooskar's first name.

### 6. **CO-CHAIR ELECTION**

On December 9, 2019, a small number of SSDAC members, along with staff, 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. It was the consensus of that group to establish a Co-Chair position and hold elections at the next possible meeting. Prior to this meeting, all SSDAC members were given the opportunity to self-nominate and submit a candidate statement. During the meeting the floor was also opened for any Committee member wanting to self-nominate. Committee members Sascha Bittner and Rick Wood provided candidate statements. No other members wished to be considered.

Committee members Cooley, Crip-Cooper, Rupert, Orlina, Forderer, Bittner, Marquez and Jones voted in favor of Committee member Sascha Bittner.

Committee members Ali, Bowman, Clark, Mark, Chan-Rapp, Pawooskar, Ramos, Heid, Smith, Landry, Wood, Johnson and Jin voted in favor of Committee member Rick Wood giving him majority vote and winning the election of Co-Chair.



## 7. **DDS UPDATE ON SELF-DETERMINATION PROGRAM (SDP)**

Jennifer Parsons from the Department of Developmental Services (DDS) provided the following SDP update to members.

The second selection of individuals to participate in the program took place on November 22, 2019. At that time there were 569 available spaces at the regional centers. Siblings of individuals who were previously selected were a priority at the November selection and preference was given to individuals who are age 42 years and older as this was a significantly underrepresented category at the time of initial selection. Additionally, members of the local self-determination program advisory committees or their family members were also given priority and so was ethnic diversity within each regional center. Those who were not selected will remain on the list at DDS. DDS reports that they continue to collect names at a rate of approximately 20 to 30 a month.

DDS went on to state that it is important to remember that there are now two groups of participants being reported on, those selected in 2018 and those selected in 2019. Some of the information that is being provided will be separated into those groups.

Those selected in 2018 were sent a note indicating that they had until December 6<sup>th</sup> to complete an orientation unless there were circumstances preventing them from doing so. Of the many who completed an orientation, some chose not to continue. DDS is gathering information via surveys on why some chose not to continue. The survey questions that were sent out reflect input from stakeholders including DDS' advisory group.

There are 135 people who are enrolled in the program, meaning 135 people are using their spending plans to pay for self-determination services. Of those selected in 2019, 81 have attended a program orientation. In addition, there have been 261 person-centered plans developed to inform the IPP and a reported additional 114 currently in development. There have been 306 orientations statewide. DDS reported that there are 9 FMS providers that have been vendored and they continue to have conversations with regional centers as situations with FMS' arise. Additionally, Newsletters continue to go out sharing stories of those in the program and sharing information on common questions.

DDS stated that they are refocusing on the Frequently Asked Questions, to ensure that they are updated on their website more frequently.

DDS has received 158 requests for background checks, of those, 132 of cleared to begun working. According to DDS it takes about a week to receive clearance to begin working once a complete package is received.

DDS stated that they recognize that there have been issues paying person-centered planners and they are trying to address this. They have been talking with providers and the related regional centers to help offer technical assistance. Furthermore, DDS acknowledged those bumps along the way and are open to hearing recommendations on those barriers.

DDS reported that there is a person-centered practices survey available. DDS partnered with Support Development Associates (SDA), to develop training on person-centered thinking and practices. SDA is compiling information from stakeholders to inform our understanding of the current state of person-centered practices in California.

DDS concluded their report by stating that they will continue to work in partnership with this Committee and are looking forward to information, recommendations and making self-determination a successful program as implementation continues.

Following this report, members had several questions which were transcribed and emailed to DDS following the meeting.

## 8. **TOP BARRIERS**

Committee member Judy Mark presented the draft Top Ten Barriers to Implementation of the Self-Determination Program report to the Committee for input, review and next steps. The report is a result of the Committee's October 2019 meeting, where members broke into 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 and produced a report identifying the top ten program implementation barriers.

Following the presentation, Committee member Mark agreed to incorporate the Committee's input and e-mail it out.

**9. MEETING FREQUENCY AND FUTURE MEETING ITEMS**

It was moved/seconded (Mark/Clark) and carried to meet four times per year, pending available funding. (Unanimous, see page one for a list of voting members)

**10. PUBLIC COMMENT**

None.

**11. ADJOURN**

The meeting was adjourned at 4:26 P.M.

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June 9, 2020

**AGENDA ITEM 6.  
INFORMATIONAL ITEM**

**STATE COUNCIL ON DEVELOPMENTAL DISABILITIES – SSDAC**

***Local SDAC Report***

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Committee members will provide a brief report on the status of program implementation at their regional centers. Several of the Committee members submitted written reports, which are attached, others have chosen to provide verbal reports.

**Attachments**

Alta California Regional Center Report  
Central Valley Regional Center Report  
Far Norther Regional Center Report  
Golden Gate Regional Center Report  
Kern Regional Center Report  
Regional Center of the East Bay Report  
Redwood Coast Regional Center Report  
San Andreas Regional Center Report  
South Central Los Angeles Regional Center Report  
San Diego Regional Center Report  
San Gabriel Pomona Regional Center Report  
Tri-County Regional Center Report  
Valley Mountain Regional Center Report  
Westside Regional Center Report

***Generally, what is the status of the Self-Determination Program (SDP) at your Regional Center? How many people are in SDP?***

179 clients were originally selected by DDS. 88 were selected for the second pull. Of those, 32 indicated they were satisfied with current services. (8 were from one family.) 6 orientations are scheduled from now until June 30 using online technology. Two participants are in the Self-Determination Program. One participant will enter the program on June 1, for a total of 3.

15 participants are working on their person-centered plans, 4 are completing their Self-Determination IPP, 4 are in the process of selecting their Financial Management Service.

***Has your SDAC made a plan to spend DDS funds for the local advisory board? If so, what's your plan? Has your SDAC been able to spend any of those funds?***

The ACRC SDAC meets every two months. We had an initial discussion about the funds at our March meeting, but did not make a decision at that time. Our region covers a large section of northern California with 10 counties. Our concern is how we can fully engage with all of the DDS selected participants on matters concerning Self-Determination. Spending the DDS funds will be a topic at our next meeting on July 8.

***What, if any, new barriers are your regional center seeing in light of the COVID pandemic? How is your regional center addressing them?***

ACRC staff has indicated that sheltering-in- place has definitely made it more difficult for participants/families to canvas their respective communities for service providers. Everything has slowed down. Another issue raised by participants/families is the availability of live scan finger printing. From the discussion, it appears that live scanning should still be available. It was also clarified by ACRC staff that the live scan finger printing is required for anyone providing personal care **and** if the participant/family requests it for other services such as driving.

ACRC continues to move forward with the Self-Determination Program using technology for communication and any other supports to assist participants/families to enter the program, and also to provide support as needed within the program.

***What is your regional center doing to continue the self-determination program during this time?***

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***Generally, what is the status of the Self-Determination Program (SDP) at your Regional Center? How many people are in SDP?***

Currently, there are 8 people in the SD, as of June 1. There are 110 individuals who have completed the orientation and in various stages of completing the process to enter self-determination. We have about 14 people who require orientation. CVRC, LAC, and SCDD will have their first Zoom orientation at the end of June. Participants are working on the PCP process, certifying their budget and developing their spending plans. Other tasks include identifying the FMS and meeting their criteria for enrollment, as well as finding staff and services to address the goals to provide a life of choice and responsibility. PCP training is on-going.

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***Has your SDAC made a plan to spend DDS funds for the local advisory board? If so, what's your plan? Has your SDAC been able to spend any of those funds?***

We have a working document developing short term and long term goals that include addressing the general needs for program support, participant support, with increased community awareness. This involves LAC hospitality, communication, transportation, PR and educational materials. We are including specific outside training by experts in the fields of PCP and IF. We are hoping to share info on what trainings we are all doing to share costs, as well as information. We are making a huge effort to address disparity issues with translation and interpretation services. SCDD is working on the IF training and networking. We have a basic timeline and budget.

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***What, if any, new barriers are your regional center seeing in light of the COVID pandemic? How is your regional center addressing them?***

Participants have many concerns to address and SD is not a priority to complete at this time. The budget is taking time to complete in the RC. We are in the process of encouraging more IF education and participation, with the concern of quality services.

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***What is your regional center doing to continue the self-determination program during this time?***

The service coordinators continue to provide support to the current participants from their home base via Zoom, phone or MStears. They adapted to the needs of clients and families.

We have convened 2 LAC meetings via ZOOM with 20-30 participants. We continue to collaborate regarding the needs of the program now and when the healthcare recommendations are lifted.

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**Generally, what is the status of the Self-Determination Program (SDP) at your Regional Center? How many people are in SDP?**

FNRC received 60 slots for FNRC eligible participant. Individuals have been notified. Twenty participants have enrolled:

Eighteen individuals are awaiting orientation

Forty individuals have completed the orientation

Twenty-five individuals have opted out of the selected participants this includes the second set of names pulled.

Twenty-two have completed spending plans

Thirty-three have completed the budget

**Has your SDAC made a plan to spend DDS funds for the local advisory board? If so, what's your plan? Has your SDAC been able to spend any of those funds?**

Proposal has been made to create a marketing video that can be located on the website.

Video can be utilized for the following:

Sharing the success stories

Using as part of the orientation

Updating the current brochure for additional languages, pictures of current participants and printing the brochure in color

**What, if any, new barriers are your regional center seeing in light of the COVID pandemic? How is your regional center addressing them?**

The obvious barrier is the group orientation.

FNRC is working on a system to record the orientation and having a question and answer session.

FMS ability to purchase items for families

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*What is your regional center doing to continue the self-determination program during this time?*

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Continuing with the development and the spending plan

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Addressing the need to develop an online orientation

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Conducting quarterly meetings with participants to review their SDP services and cost statements sent by FMS

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***Generally, what is the status of the Self-Determination Program (SDP) at your Regional Center? How many people are in SDP?***

- SDP continues to move along at GGRC. We have **three** individuals who have completed the process and implementing their Spending Plans.
  - A number of Person-Centered Plans have been completed, with some working on the development of Individual Budgets and Spending Plans.
  - A bulk of folks from the 2<sup>nd</sup> Selection group still require an orientation. This is being addressed. The plan is to arrange orientations with individual/family, social worker, and SDP Supervising Social Worker via Zoom or phone conference, utilizing power point orientation on shared screen.
  - Total of 67 SDP participants remain, including the 3 folks implementing their Spending Plans.
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***Has your SDAC made a plan to spend DDS funds for the local advisory board? If so, what's your plan? Has your SDAC been able to spend any of those funds?***

Our SDAC is in the process of planning how the funds will be spent. It has been decided to use some of the funds to hire a person to provide Independent Facilitator training. Other uses will be for translation services.

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***What, if any, new barriers are your regional center seeing in light of the COVID pandemic? How is your regional center addressing them?***

Providing face-to-face orientations with families – especially monolingual families – impedes the ability to do these meetings efficiently. Currently working on providing orientation to a Spanish-speaking parent with the help of the social worker to translate. We'll use Spanish version of the orientation's power point on shared screen.

The opportunity to meet the individual and interact with them is much different. Mostly, meetings for our younger individuals are with the parent. The child has often been to the side, making it impossible to see him/her and engage in conversation or interaction. Using Zoom has been helpful in meeting/seeing each other, but again, interaction is limited. Additionally, there have been technical difficulties which have affected the flow of the meeting. As needed additional meetings are scheduled.. The great thing about Zoom has been that we can share the screen and go through a form together, such as the Individual Budget calculation tool.

We have had phone conferences with families which eliminates the technical barriers of Zoom. Those meetings have gone well. Again, additional meetings are scheduled as needed.

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*What is your regional center doing to continue the self-determination program during this time?*

GGRC already had remote work access prior to the Shelter-in-Place order. The SDP Supervising Social Worker has been communicating with GGRC social workers who set up with the appropriate participants via Zoom or phone conference for:

- Individual orientation meetings
- Person-Centered Plan meetings
- Individual Budget meetings

The different GGRC departments (i.e. Accounting Dept./Fiscal Unit; Vendorization; Community Services Unit; RCS) are working together via emails and phone calls to move SDP process forward for individuals.

SDP questions, concerns, and issues are fielded by SDP Supervising Social Worker via email, Zoom, and phone. SDP Sup. SW confers with her supervisor (Director of RCS Services) and/or DDS-SDP staff for consult via phone or email.

The SDLAC has continued to meet via Zoom or phone every 2<sup>nd</sup> Tuesday of the month. Agenda prepared by SDP Sup SW and reviewed by SDLAC co-chairs, SCDD Advisor/Regional Manager, GGRC advisor/ RCS Director of Regional Center Services, and GGRC Advisor/Executive Director as per usual procedure. Agenda posted in GGRC website following review. We have had public participation at these meetings during the Shelter-in-Place.

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***Generally, what is the status of the Self-Determination Program (SDP) at your Regional Center? How many people are in SDP?***

Generally, KRC staff is diligently moving forward with orientations, development of person centered plans, budget certifications, and spending plans. Currently 27 of the 29 Pilot participants have transitioned to SDP. 1 participant will transition by the end of May, 2020. The final participant will likely transition in June, 2020.

From the 2018 draw of non-Pilot consumers, there were 36 selected (the draw was greater than 36, but several declined to participate), all of whom have completed orientations. Only 1 has transitioned to SDP. 2 have dropped off. There have been budget challenges.

From the 2019 draw of 70 consumers, all but 11 have completed orientations. None have transitioned yet.

A success story is that in Inyo and Mono Counties, 7 consumers were included in the 2019 draw. Of those, 5 are nearing completion of their person centered plans. The process from orientations to PCP completion has been only 2-3 months. The remaining 2 have not decided yet whether to go forward.

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Barriers include difficulty in navigating budget tool, availability of IFs, resistance by some FMS's to take on new clients, and completing person centered plans. Biggest barrier is delay in background checks.

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***Has your SDAC made a plan to spend DDS funds for the local advisory board? If so, what's your plan? Has your SDAC been able to spend any of those funds?***

No. Discussion to be included in agenda for June 8, 2020 meeting. Update will be provided.

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***What, if any, new barriers are your regional center seeing in light of the COVID pandemic? How is your regional center addressing them?***

More respite requests; closure of day programs without substitute activities; lack of supplies such as diapers, wipes; lack of food; completion of in-person orientations (alternatives include Zoom, Facetime, and telephone). RC staff is addressing issues and is proactively reaching out to all participants and those whose plans have not yet been completed.

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***What is your regional center doing to continue the self-determination program during this time?***

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***Generally, what is the status of the Self-Determination Program (SDP) at your Regional Center? How many people are in SDP?***

Almost all selectees have been oriented but movement after that step has been slow. We have one person in SDP and another one who was close as of our May 4 meeting. Fifty-four spending budgets have been sent out to our 154 selectees but we don't know how many have been agreed to or need adjustments for changes in circumstances or unmet needs. Regional Center has paid for, or is in the process of paying for, 23 person-centered plans.

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***Has your SDAC made a plan to spend DDS funds for the local advisory board? If so, what's your plan? Has your SDAC been able to spend any of those funds?***

We are finalizing our plan at our next meeting on June 1. We can report on this on June 9.

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***What, if any, new barriers are your regional center seeing in light of the COVID pandemic? How is your regional center addressing them?***

Barriers: Some participants and families have immediate issues regarding health, program closures or new service needs. Service coordinators (case managers) are trying to respond to immediate issues while working remotely.

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***What is your regional center doing to continue the self-determination program during this time?***

Continuing to do internal steps of review. Hired a new Self-Determination Program Specialist as the prior one left at the beginning of January. The new SD specialist began on May 6 and will oversee the program.

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***Generally, what is the status of the Self-Determination Program (SDP) at your Regional Center? How many people are in SDP?***

Self Determination is moving along slowly. At the current time all available slots have been filled.  
New 40, 25 Pilot – Total 65

***Has your SDAC made a plan to spend DDS funds for the local advisory board? If so, what's your plan? Has your SDAC been able to spend any of those funds?***

The plan is not final and will be discussed again in June.

***What, if any, new barriers are your regional center seeing in light of the COVID pandemic? How is your regional center addressing them?***

The COVID pandemic has slowed the "process further by not being able for participants to meet together. All plans for "Meet and Greet meetings were cancelled. Orientation is being done one person at a time. Zoom type meetings are not always successful due to the fact that internet connections are not available in much of the region.

The Pandemic is a health crisis and all regional center staff attention has been placed on the health and safety of their clients.

***What is your regional center doing to continue the self-determination program during this time?***

We have begun our meetings again. Members chose not to have meetings in March, and April. One was held in May and another is planned in June.

***Generally, what is the status of the Self-Determination Program (SDP) at your Regional Center? How many people are in SDP?***

For San Andreas Regional Center, there are 16 selectees who still need to receive orientation. SARC. 14 Spending Plans Complete, 18 plans certified, and 7 in negotiation with FMS.

At the most recent SDAC meeting, Members adopted membership guidelines which give greater direction for the composition and length of terms for the committee.

***Has your SDAC made a plan to spend DDS funds for the local advisory board? If so, what's your plan? Has your SDAC been able to spend any of those funds?***

No plans have been made it will be a topic of discussion at the June SDAC meeting. SARC reports waiting for further clarification from DDS

***What, if any, new barriers are your regional center seeing in light of the COVID pandemic? How is your regional center addressing them?***

Some families continue to move forward with there plans. Others feel stuck. To address the need the Independent Facilitators will be hosting a video-conference Selectee Mixer for June 4<sup>th</sup>. SDAC is planning to provide Independent Facilitator Training for latter in June. The primary provider of Person Centered Thinking Training has not held any meetings since the emergency. Families are expressing a need for PCP trainings.

SDAC was informed of the loss of Cheryl Hewitt the chair of the committee. She passed away on May 22, 2020. Cheryl was a great advocate and believer in Self Determination. She will be missed. A memorial is being planned for her in late June.

At the June meeting, Nominations for the Chair will be added to the agenda, with elections likely at the July meeting. Currently Martha Johanson is the acting chair.

***What is your regional center doing to continue the self-determination program during this time?***

SDAC continues to meet, SARC staff is working with families as they progress toward Self Determined Plans. As families adjust to the new stay in home orders, the aim is the resume staying active in Self Determination Plan Development and Implementation.

***Generally, what is the status of the Self-Determination Program (SDP) at your Regional Center? How many people are in SDP?***

SCLARC is allotted 112 slots for SDP. Including individuals who did not attend orientation, but were not removed from the list after December 2019, there are 122 individuals on the current list (not formally marked as withdrawn.) Fourteen participants have withdrawn, typically citing satisfaction with current services and/or feeling they did not have the time/ability to manage the program; this leaves 108 participants active. Of those 108, 86 have completed orientation as of 5/21/2020, with 22 outstanding. Seven participants have completed person-centered plans, with approximately 4 in progress. Three budget meetings have been held (all since March 2020), and two budgets are certified. One spending plan is completed and IPP completion is anticipated by 5/31/2020, with the hope of starting services under SDP effective 6/1/2020.

***Has your SDAC made a plan to spend DDS funds for the local advisory board? If so, what's your plan? Has your SDAC been able to spend any of those funds?***

SCLARC and the SDAC are working together to spend the DDS funds. SCLARC was hindered by the COVID-19 pandemic in providing specific dollar amounts to the committee in its' May meeting; it is anticipated these dollar amounts will be available by the June 2020 meeting. The following items have been discussed: Technology (laptop(s)/iPad/etc.) for meetings (i.e. for GoToMeetings during the COVID-19 pandemic, as well as to present PowerPoints during SDLAC meetings, Orientations, etc.), translation equipment for participants to receive interpretation at meetings, retroactive and ongoing funding for interpretation services at the SDLAC meetings, informational Sessions, orientations, etc., printing/editing/purchasing of an SDP guide book (currently reviewing Disability Voices United's and TCRC's to determine which one meets needs better), and retroactive funding for a resource fair that was held for SDP participants in February 2020. While no money has yet been spent, it is expected to be approved/agreed upon in the June meeting and encumbered for/spent beginning in the 2021 fiscal year.

***What, if any, new barriers are your regional center seeing in light of the COVID pandemic? How is your regional center addressing them?***

Families want to attend orientation, but are unable to devote the time due to the needs of the child(ren) in the home (such as childcare, needing to use the computer, needing assistance with schoolwork, etc.), including those who are home from school and day program. \*In order to address this, SCLARC is planning on holding orientation(s) after school lets out for the summer, as well as later in the day, which will also assist families that have had difficulty attending orientation due to their work schedule. SCLARC will also consider a Saturday orientation again if needed. In addition, SCLARC split the typically four hour orientation into two, two hour sessions to make it more manageable

Families want to attend orientation, but do not have the technology (i.e. email/computer/laptop) to access the meetings \* In order to address this, SCLARC uses a platform (GoToMeeting) that can be called into via a landline or non-smart phone, and is able to email and/or mail out handouts prior to the meetings. In addition, when regulations are relaxed further, SCLARC is planning on allowing individual families to come to the Regional Center to view the orientations using SCLARC's technology and appropriate social distancing measures.

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Inability to have in-person meetings impacting person-centered plans, as well as the ability to have budget meetings, certify budgets, hold SDLAC meetings, etc. \* To address this, SCLARC has shared the feedback of person-centered planners who have found benefits to remote meetings (i.e. that more members of the circle of support are able to participate than might otherwise be expected) with participants; this will also be shared in phone calls made in the next month (see further detail under what SCLARC is doing to continue SDP during this time). In addition, budget meetings and SDPLAC meetings have been held remotely (via GoToMeeting) and email discussions/certifications of budgets have occurred. Remote SDPLAC meetings are advertised via email, text message, SCLARC's main Facebook page, SCLARC's Self-Advocates Committee Facebook page, and notification on SCLARC's website in both English and Spanish.

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Limited responses from DDS on COVID-specific questions, as well as limited SCLARC-staff availability to address SDP concerns due to devotion to the COVID crisis \* In order to address this, SCLARC has scheduled and held specific phone meetings with DDS when questions need to be answered, and staff have continued to be available to participants and families for SDP issues, with some reassignment of staff occurring as needed to ensure coverage. All orientations, informational sessions, SDPLAC meetings, etc., have been held as planned.

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Difficulty contacting individuals about orientation (i.e. no response to phone calls or emails), as also demonstrated by lack of response to COVID-19 wellness checks, due to individuals/families otherwise being preoccupied with the crisis \* SCLARC addressed this by personally calling all individuals who needed to complete orientation to invite them to the May 2020 orientation, and will do so again for the June orientation. In addition, an email invitation was sent in English and Spanish to all individuals with email addresses on file, which will be sent again in June 2020; the May 2020 email invitation was at the suggestion of the committee and the first time SCLARC had done this. In addition, SCLARC is not currently inactivating cases due to lack of response.

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Participants/Families RSVP for orientation, sometimes even confirming the morning-of, but do not log on/participate/respond to phone calls at the time of the meeting \* SCLARC is addressing this by continuing to invite these individuals to upcoming orientations, logging attendance, and providing reminders the morning of the meetings, as well as technical assistance with logging on.

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### *What is your regional center doing to continue the self-determination program during this time?*

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\*March 2020 – letters were mailed to all individuals who had not completed orientation, as well as those who had completed orientation but had not yet completed a person-centered plan, to provide them with resources and encourage them to move forward. These letters included the schedule of orientations and resources for Person-Centered Planners, Independent Facilitators, and FMS companies, as appropriate to each individual's specific situation, and also encouraged participants and families to attend the SDPLAC meetings.

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\*March and May 2020 – SCLARC Program Manager met via videoconference with FMS companies

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\*April and May 2020, and ongoing – SDPLAC meetings were held via GoToMeeting/remotely. Invitations were sent via Facebook (Self-Advocate Committee and SCLARC's main page), text message, email, and SCLARC's Facebook page, in English and Spanish. Interpretation services were available remotely.

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\*May 2020 and ongoing – Each participant who still needs to attend orientation was called and emailed individually to attempt to secure an RSVP. Participants were also called to remind

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them of the orientations the morning of, and technical assistance with logging on was provided as necessary. Barriers to participation were recorded, presented to the committee, and addressed, as indicated above.

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\*May 2020 and ongoing – As the remote accessibility of the SDPLAC meetings has actually increased attendance, SCLARC is exploring the possibility of having some remote availability present on an ongoing basis, while remaining in compliance with Bagley-Keene rules, when they are no longer relaxed (i.e. having a second/satellite location with a member of the committee, a teleconference streaming the main meeting, and a SCLARC staff member available; it is anticipated that this may be done at SCLARC’s South Gate office, which is located in the Southeast portion of SCLARC’s catchment area, where there is traditionally more disparity in services, and would respond to the request of community members indicating they would like to participate but have been hindered by the distance to the main office in LA)

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\*May/June 2020 – Each participant that has completed orientation, but has not yet completed a Person-Centered Plan, will be contacted individually. A questionnaire will be completed, and resources will be provided if needed (i.e. for Person Centered Planners, Independent Facilitators, FMS, etc.). Any questions and/or barriers will be reported to the appropriate SCLARC staff, who will contact individuals/families as needed to follow up. The barriers and SCLARC’s response to them will be presented to the committee for further input.

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\*April 2020 – All staff assigned to SDP (i.e. team leaders, Program Managers, Service Coordinators, etc.) were retrained in SDP by having the orientation presented to them again, in order to have the opportunity to ask questions and receive clarification now that the program is more fleshed out.

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\*Ongoing – Staff have continued to be available via phone, email, and video conference for budgets, questions, spending plans, etc., and the process has continued to move forward for individuals as a result; both budgets certified, and 2 out of three budget meetings, happened during COVID-19, and it is anticipated that the first person will begin services during COVID-19!

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*Generally, what is the status of the Self-Determination Program (SDP) at your Regional Center? How many people are in SDP?*

**Number of People Enrolled - 23**

Number in between orientation and enrollment - 77 (PCP/Budget in progress – 60; Spending plan/IPP pending – 17)  
Attended orientation only – 46  
Have not attended orientation yet – 31  
Disenrollments since March 2020 – 24

**Reasons for Disenrollment:**

- Program still too new.
- Perception of amount of work/planning required
- Plans to stay with same vendored service providers currently using.
- Small budget.

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*Has your SDAC made a plan to spend DDS funds for the local advisory board? If so, what's your plan? Has your SDAC been able to spend any of those funds?*

San Diego Regional Center Local Advisory Committee reviewed the directive and priority areas issued by DDS in collaboration with community stakeholders: SDP participants, families, SDRC consumers, SDRC staff, service providers, independent facilitators, person-centered plan providers and other community members.

Based on stakeholder input, the committee identified needs, priorities, and strategies to develop a local plan. The overall goals of the plan are to ensure individuals and families thrive in the program by promoting full access to anyone who receives regional center services, develop a support system to facilitate enrollment and successful implementation, and build community capacity to support participants and families, now and in the future.

Priorities include stakeholder engagement, education, and training, expanding support systems and networking opportunities, community collaboration and advocacy.

Strategies: Develop effective pathways and best practices for participants to access the SDP: offer virtual/live information sessions, orientations, training and conferences on key topics such as person-centered planning, budget and spending plans, recruit subject matter experts to provide training, convene follow-up “clinics” (post orientation) to provide individualized technical assistance and/or needs-based support; offer virtual/live networking and collaboration sessions for participants, families and providers; create a SDP peer mentor/ambassador program; and address barriers due to limited technology and socioeconomic, culture or language issues. The committee is on track to finalize and approve a plan within the DDS timeline for submission.

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***What, if any, new barriers are your regional center seeing in light of the COVID pandemic? How is your regional center addressing them?***

The committee resumed meetings in April. We devoted most of the time on the SDP funds.

Barriers/Issues/Strategies: We are moving orientations and services to virtual platforms. There are some concerns re: the lack of technology or limited proficiency/comfort level may be barrier for some people. Also, the current climate is not conducive for hiring staff and/or accessing community resources. We will continue to identify potential barriers and make recommendations to our local regional center.

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*What is your regional center doing to continue the self-determination program during this time?*

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***Generally, what is the status of the Self-Determination Program (SDP) at your Regional Center? How many people are in SDP?***

First set of mandatory trainings to selected families into SDP took place prior to COVID 19 shelter in place order. Plans for the second set of training did not take place due to the Pandemic About 95 consumers were select at SG/PRC to SDP, recently handful have their budget certified, and couple working on their spending plans, However, background check – Live scans are an obstacle due to current COVID 19 environment. A DDS should seek a Waiver to overcome this condition. SDP LAC continues to take place via ZOOM, actually more public attendance occurs with such virtual meeting environment.

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***Has your SDAC made a plan to spend DDS funds for the local advisory board? If so, what's you're your plan? Has your SDAC been able to spend any of those funds?***

At least 90% of the funds were jointly agreed to be allocated to “Support Coaching for Transition to SDP”, and “Collaborative Groups Workshops”. SG/PRC has two RFPs out for these items. The remaining 10% were allocated to “Additional Identified Needs” (currently exploring providing child care during family training). The LAC met at special (additional) meeting on May 26, 2020 to further discuss and obtain status of the above funds.

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***What, if any, new barriers are your regional center seeing in light of the COVID pandemic? How is your regional center addressing them?***

Live Scan (Background Check) as FMS looking for a Waiver due impractical process during COVID 19. Similar Waiver/Action was approved to IHSS providers.

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***What is your regional center doing to continue the self-determination program during this time?***

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***Generally, what is the status of the Self-Determination Program (SDP) at your Regional Center? How many people are in SDP?***

TCRC has 6 enrolled in the new SD program and 2 two that are in the pilot project in transition to move over. One of these should be ready to make the change by June 1<sup>st</sup>.

Although TCRC has made the information widely available to the community about Self - Determination, there is minimal interest about the program. TCRC's advisory committee will be discussing additional opportunities to inform those served by TCRC about the program

***Has your SDAC made a plan to spend DDS funds for the local advisory board? If so, what's you're your plan? Has your SDAC been able to spend any of those funds?***

A portion of the funds have been used to publish our training workbook and purchase food for both our orientations and monthly committee meetings. We will be making the final determination during our June meeting of how the rest of the funds will be used to address SD in our community. TCRC's Person Centered Planning Coordinator will be presenting proposals around virtual planning meetings. The committee will take these into consideration when discussing ideas to advance SD.

***What, if any, new barriers are your regional center seeing in light of the COVID pandemic? How is your regional center addressing them?***

With limited community and vendor services available during C19, we've had a couple of our participants request a new planning team meeting to amend their spending plan and IPP in order to use different services that were / are available during this time. We have 5-6 who are actively planning in anticipation of C19 restrictions being lifted in order to move from traditional services to SD once the identified services and supports are available to access. Most of those who were moving forward have decided to hold off until more is known (post C19) and it is safe to access services.

***What is your regional center doing to continue the self-determination program during this time?***

TCRC has 6 people from the second round selection who still need to attend an orientation. They are contacting those individuals to see if they would like to hold a revised version of the orientation via Zoom or wait until we are allowed to hold an in-person meeting. In addition In addition, during conversation with other RC's TCRC will be exploring the possibility of posting a narrated version of our orientation online.

***Generally, what is the status of the Self-Determination Program (SDP) at your Regional Center? How many people are in SDP?***

Currently 14 people are on the program, 72 of 110 have attended the orientation, 14 people chose to not participate, 30 people need a PCP/IPP, PCP/IPP has been held for 42 people, 13 people are working on budgets and 15 have signed budgets and are developing their spending plans. PCP/IPP meetings continue to be held 4 meetings in March since Stay at home was implemented, 6 in April, 6 in May as of the writing of this report and 5 already scheduled for June.

SDAC meets the third Thursday of every month via Zoom

SDP Orientation Trainings were held in person January, February and March. No trainings were held in April or May. Next scheduled training is June 10<sup>th</sup> via Zoom

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***Has your SDAC made a plan to spend DDS funds for the local advisory board? If so, what's your plan? Has your SDAC been able to spend any of those funds?***

We have ordered the Welcome to Self Determination Training book that was developed by TCRC to accompany our training for the families that have been selected.

We were in the planning process for a SDP Fair with speakers about different part of the program, vendors, RC staff, consumers and families. Do to COVID this planning has been placed on hold.

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***What, if any, new barriers are your regional center seeing in light of the COVID pandemic? How is your regional center addressing them?***

The largest barrier seems to be with the development of spending plans. Business are closed so it is making it difficult to determine some of the services. Some families are also choosing to wait to move forward with the program until businesses have reopened. A few families want to wait to begin the PCP/IPP process until they can meet in person and the COVID concerns have passed. Some families are uncomfortable with or do not trust the use of electronic platforms for meeting communication.

One barrier that has come up is the need for making changes to the spending plan. The Regional Center is addressing it case by case as it comes up.

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***What is your regional center doing to continue the self-determination program during this time?***

The regional center continues to hold consumer meetings by Zoom. Budgets are being developed and they are providing assistance as much as possible with developing the spending planes. Forward progress for Self-Determination has not stopped. In fact, it seems to have increased because there is not traveling to meetings involved. VMRC also has another SDP Service Coordinator. Training will restart monthly on June 10<sup>th</sup>. Service Coordinators continue to make contact with families to offer support during this time.

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Good afternoon, below is the additional information that was added to the original filled out form SCDD received from VMRC's staff yesterday. In this email I also attached the filled out form with this additional information on it.

***This is Mariela Ramos VMRC's Local Advisory Committee Chair: VMRC staff filled out this form and then sent it to Robin Maitino (SCDD) via email; however I was not included in that email but then I downloaded the form and added some of my own information for the Statewide Committee Members. The information I'm providing is based on what I've seen at our Local Advisory Committee and on the only SD participant I know. The barrier that this family has reported is FMS is taking too long to pay her son's providers.***

***The information provide below in dark letters is data that was provided by vmrc staff. The Local Advisory Committee doesn't have access to the SD participants list from our Regional Center, therefore can't corroborate the information below. VMRC's SD participants don't attend our Local Advisory Committee Meetings. We don't have a way to actually hear from them on how they are doing. That is definitely a barrier.***

***These is additional information I requested from vmrc and received from its staff:***

Person Centered Plans Completed by VMRC Service Coordinators-- 32

Person Centered Plans Completed by an Independent Facilitators-- 2

Participants that are already in the program using the sole employer model for FMS--1

Participants that are already in the program using the co-employer model for FMS--9

Participants that are already in the program using the Bill payer model for FMS—4  
VMRC Ordered 100 Books in English (\$2195.00 or \$21.95 each) and 25 in Spanish (\$725.00 or \$29.00 each)= \$2920.00

Have a great day!!

Mariela Ramos  
VMRC's Local Advisory  
Committee Chair



***Generally, what is the status of the Self-Determination Program (SDP) at your Regional Center? How many people are in SDP?***

There are currently 4 people in the SDP with 4 more waiting to enter. This is out of 68 people in the program.

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There are 25 participants with certified budgets and 7 spending plans approved.

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There are still 9 participants who need to fulfill their orientation.

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***Has your SDAC made a plan to spend DDS funds for the local advisory board? If so, what's your plan? Has your SDAC been able to spend any of those funds?***

Several months ago we voted to dedicate \$4,000 in funds toward attending SSDAC meetings in person. Other funds would be spent on in-person events, but that may not happen anytime soon.

At our monthly meeting last night, 5/27, we talked about spending money to pay for assistance from FMSs to develop budgets for participants. We will take a vote on it at June's meeting.

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***What, if any, new barriers are your regional center seeing in light of the COVID pandemic? How is your regional center addressing them?***

The biggest barrier is the requirement for fingerprinting for staff. That is what is keeping the four people from entering now. The second barrier is that some families aren't keen on having their person-centered plans conducted virtually.

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***What is your regional center doing to continue the self-determination program during this time?***

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We continue to meet monthly but now through Zoom. In fact, our participation and attendance has increased because there is no need for child care. We have also been inviting members of local committees from other regional centers, which has been excellent for information sharing. And we have participants from other regional centers who have questions that can't seem to get answered.

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But this pandemic will have a long-term effect and we are trying to be cognizant of that. Not being with each other personally means less support and more isolation. This is why we will continue to meet monthly by Zoom and encourage people to move forward with SDP.

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June 9, 2020

**AGENDA ITEM 7.  
INFORMATIONAL ITEM**

**STATE COUNCIL ON DEVELOPMENTAL DISABILITIES – SSDAC**

***Breakout: Barriers to Self-Determination in the Age of COVID-19***

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Committee members will continue the work they started on in February when they received a draft report on the Barriers to Implementing the Self-Determination Program (SDP). The Co-Chairs believe that barriers which existed at that time have been exacerbated by the COVID-19 pandemic, and new barriers have surfaced. The purpose of this agenda item is to engage all members of the SSDAC in a discussion of barriers to self-determination (SD) in order to arrive at consensus recommendations to overcome them.

Additionally, the Co-Chairs will share the attached results of a survey of persons interested in the SDP conducted by Disability Voices United identify and illustrate barriers to SD.

Members will be divided into four distinct and random groups, which will engage in a discussion of specific barriers leading to recommendations to be presented to the entire Committee for its approval and submission to the State Council and the Department of Developmental Services.

**Attachments**

Discussion and Recommendations of Barriers to Implementation of the Self-Determination Program by Co-Chair, Rick Wood

Survey by Disability Voices United Finds People with Disabilities Suffer Disproportionate Negative Impacted by Coronavirus Pandemic Shutdown

# **STATEWIDE SELF-DETERMINATION ADVISORY COMMITTEE**

## **AGENDA ITEM**

**JUNE 9, 2020**

### **DISCUSSION AND RECOMMENDATIONS OF BARRIERS TO IMPLEMENTATION OF THE SELF-DETERMINATION PROGRAM**

#### **Introduction.**

The Statewide Self-Determination Advisory Committee (“SSDAC”) received a draft report on barriers to implementation of the Self-Determination Program (“SDP”) at its February 5, 2020 meeting. Barriers which existed at that time have been exacerbated by the Covid-19 pandemic, and new barriers have arisen. The purpose of this agenda item is to engage all members of the SSDAC in a discussion of barriers to self-determination (“SD”) in order to arrive at consensus recommendations to overcome them.

The three-year phase-in period in which 2,500 persons have been chosen to participate in the SDP will end on June 7, 2021, at which time all persons served by Regional Centers will be eligible to become self-determined. In order for the SDP to be successful, the existing barriers must be overcome.

The results of a survey of persons interested in the SDP conducted by Disability Voices United identify and illustrate barriers to SD. The survey and its results will be distributed to members of the SSDAC.

The SSDAC will be divided into four distinct groups, and members will be randomly assigned to each group, which will engage in a discussion of specific barriers leading to recommendations to be presented to the entire SSDAC for its approval and submission to the SCDD and DDS.

**Barrier #1. Delay in Implementation of SDP.**

- DDS delay in seeking and obtaining approval of Waiver application. This has resulted in lack of enthusiasm for the SDP and a loss of momentum.
- Regional Center (“RC”) implementation has been unequal and inconsistent. This has resulted in persons being discouraged from participating in the SDP.
- RCs have inconsistently addressed under-served populations and unmet needs. This has resulted in persons questioning why they should transition to the SDP.
- “Paradigm shift” in which persons believe that they have individual freedom of choice and the ability to control their own lives has not yet occurred.
- Background checks should be expedited. During the pandemic, they should be suspended for personal care providers who have previously provided or currently provide services to persons who are in the process of enrolling in the SDP.
- Other: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_.

**Discussion and Recommendations.**

- DDS and RCs should share with SD Local Advisory Committees (“LAC”) statistics on number of participants, pace of enrollment, etc.
- DDS should conduct surveys of persons who have enrolled and those who have dropped out of the SDP, and share the results with RCs and LACs. Once received, the SSDAC should analyze results and make recommendations to encourage increased participation in the SDP.
- There should be mandatory training of RC staff to increase consistency of implementation.
- SSDAC should establish benchmarks for implementation and each LAC should monitor them.
- SSDAC should share models of success and encourage LACs to apply lessons learned to local implementation.
- Other: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_.

## **Barrier #2. Lack of Guidance by DDS.**

- DDS has been slow to issue guidance and directives to RCs and SDP participants. This has resulted in RCs not having consistent implementation guidelines. Participants have not understood basic mechanics of SD, leading to a loss of momentum and unacceptable dropout rates.
- Processes within the SDP have been developed by RCs who are accustomed to rules, forms, procedures, and they have therefore not adjusted to the new SD normal, in which participants are “in charge.” Flexibility and creativity are hallmarks of SD. “Bureaucratization” of the SDP has discouraged potential participants, leading to high drop-out rates.
- Underserved communities, face additional obstacles to SD. Anecdotal evidence suggests that racial and ethnic disparities are perpetuated in the SDP.
- DDS has not been proactive in its oversight of implementation of the SDP and has not required accountability by RCs. This has resulted in a slow roll-out of the SDP, with less than 10% of eligible participants actually enrolled.
- Other: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_.

## **Discussion and Recommendations.**

- DDS should issue clear and consistent guidance and directives to RCs and LACs.
- Questions and comments by LACs should be shared among all members of the SSDAC.
- DDS should establish and update FAQs on its website.
- RCs should consult with LACs on all matters of implementation and directives from DDS. RCs should draw on the experiences of SD Pilots.
- Directives, training materials, information and notices must be formally translated into Spanish and other languages.
- DDS should monitor implementation of the SDP by RCs of underserved participants and those with prior unmet needs in order to avoid racial and ethnic disparities.
- DDS should prioritize systemic oversight of and require strict accountability by RCs.
- Other: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_.

**Barrier #3: Lack of Training.**

- Required information meetings and orientations lack plain-language, simple explanation of the SDP. This has caused confusion among those persons attending, leading to unacceptable drop-out rates by those who previously expressed interest in the SDP.
- Similarly, there is a lack of mandatory, comprehensive training of RC staff. This has led to misconceptions by RC staff which has resulted in dissemination of incorrect information to those who are interested in participating in the SDP. Service coordinators/case managers know very little of the SDP, but occupy a front-line position in implementation.
- Difficulty by RC staff to navigate the budget tool. This results in delay and perceptions of difficulty in developing a budget and spending plan.
- Other: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_.

**Discussion and Recommendations.**

- DDS should develop shorter, plain language presentations. SSDAC should provide feedback to LACs and RCs.
- LAC members should conduct presentations in collaboration with RC staff.
- The Covid-19 pandemic and social distancing should not be used as an excuse to suspend trainings of RC staff and participants.
- DDS should develop mandatory consistent training regimens for RCs, and should provide oversight of trainings and outcomes.
- RCs should develop a network of service coordinators within which ideas and experiences can be exchanged.
- Other: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_.

**Barrier #4: Lack of Trained Person-Centered-Planners, FMS, Independent Facilitators, and Service Providers.**

- There are no training materials for persons interested in becoming PCP planners and independent facilitators. This has resulted in inconsistent development of plans.
- The independent facilitator “profession” has yet to develop. This has resulted in excessive reliance on service coordinators by participants in the SDP.
- The requirements of vendorization of FMS are burdensome, thereby limiting the number and variety of FMS available to participants. FMS have experienced delays in receipt of funds to pay for clients’ services and supports.
- Service providers who provide services and supports in the traditional delivery system are unfamiliar with and lack knowledge of the SDP. This constricts the availability of service providers for SDP participants. This impacts the creativity and individuality of PCPs.
- Other: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_.

**Discussion and Recommendations.**

- DDS should develop materials for PCP planners and independent facilitators.
- RCs should provide trainings for independent facilitators and should provide opportunities for participants to meet and engage with independent facilitators. This should not be left to “the marketplace.” DDS should develop plan-language explanation of the role of FMS.
- DDS should provide direct oversight of FMS and require accountability. RCs must timely advance/distribute funds to FMS so as not to delay payment to providers of services and supports.
- RCs should proactively encourage and promote participation in the SDP by service providers, and in particular educate service providers about the SDP.
- Other: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_.



## Survey by Disability Voices United Finds People with Disabilities Suffer Disproportionate Negative Impacted by Coronavirus Pandemic Shutdown

Disability Voices United is a California statewide advocacy organization directed by and for people with developmental disabilities and family members.

### **NUMBER OF SURVEY RESPONDENTS**

- 441 people with disabilities and family members responded to the survey
- 13% are people with disabilities
- 87% are family members of people with disabilities

### **DISABILITIES OF SURVEY RESPONDENTS**

- Autism Spectrum Disorder
- Cerebral Palsy
- Intellectual disability
- Down syndrome
- Epilepsy
- Other development disability
- Blind or Low Vision
- Deaf or Hard of Hearing
- Physical disability
- Mental health disability
- Chronic illness
- Medically fragile
- Brain injury
- Genetic disorders
- Learning disabilities
- Apraxia

### **Most respondents live with family**

80% of respondents lived with their family.

8% lived in their own place without support staff.

7% lived in their own place with support staff.

3% lived with others in a group home or facility.

## **Racial and ethnic makeup of respondents**

34.8% of survey respondents were Latino or Latina.

33.5% of survey respondents were White.

7.3% of survey respondents were Black.

6.2% of survey respondents were Asian.

1.3% of survey respondents were Native American.

16.9% of respondents identified as “Other” or chose not to identify their race.

## **Most Respondents are Regional Center Clients**

- 84% of respondents have a developmental disability and qualify for regional center services
- Respondents represented all 21 regional centers throughout California

## **Some Regional Center Clients Still Waiting for a Call**

Despite regional centers’ claims they have reached out to all of their clients:

- 42% of respondents reported they had never been contacted
- 60% reported that they had recently tried to reach their regional center to get help during the crisis
- Almost 1/4 of those hadn’t gotten a response

## **People Need More Services, But Don’t Get Them**

- 40% asked for more services or supports from regional center to help them during pandemic
- 47% of those had not receive the services they requested
  - Reasons: No response, told they had enough services, couldn’t find staff

## **Latinos Have Much Greater Need for Services**

52% of Latinos reported asking for more regional center support. In comparison, 30% of white respondents, 26% of Black respondents, and 32% of Asian respondents asked for more regional center support.

## **People Need Support, But Are Afraid**

54% expressed concerns about having support workers in their home. They reported concerns like:

- Fear of being exposed to virus
- Person is medically fragile
- No personal protective equipment
- Person with disability won't wear mask
- Staff who are not knowledgeable

## **Programs Still Billing, But Almost Half Get No Services**

California has agreed to continue to pay for programs experiencing absences due to COVID-19; however, they must continue to provide services in person or remotely.

45% of survey respondents report they attend a congregate group day program. Of those, 93% said their day program was closed due to the coronavirus outbreak. Only 51% said they were continuing to receive services.

## **Almost Half of Students with Disabilities Not Accessing Education**

Half of respondents reported their family member was a student with an IEP (Individualized Education Program). Of those:

- 49% were not receiving education services since schools closed
- 16% did not have access to a computer or device to receive special education services

## **Reasons Given for Not Accessing Education**

- No direct teaching, even remotely
- Speech therapy through telehealth still not approved
- Took over a month for teacher to contact family Student can't sit for online learning
- Teacher only provides weekly worksheets
- No school work provided – just referral to websites
- Student is non-speaking and can't participate without communication support

## **Barriers Worsen for Self-Determination Program**

14% of respondents were part of the Self- Determination Program. The barriers they mentioned include:

- No response from regional center
- Can't get budget certified after months of trying
- Dangerous to get staff fingerprinted
- Afraid to have virtual person-centered plan
- Independent facilitator not getting paid

## **Families Not Prepared for COVID-19**

- 39% don't know what to do if someone in their household gets infected with coronavirus
- 44% have no one to care for them or their family member if they get sick
- 35% have no access to personal protective equipment, like gloves and masks, in their home
- Biggest concerns in the Latino community

## **More Latinos Not Prepared for COVID-19**

52% of Latino respondents reported they don't know what to do if someone in their household contracts coronavirus. By comparison, 29% of White respondents, 31% of Black respondents, 32% of Asian respondents, and 40% of Native American respondents reported they didn't know what to do.

## **Latinos Less Likely to Have Someone to Care for Them if They Get Sick**

40% of Latino respondents report they have somebody to take care of them if they get sick. 62% of White respondents, 58% of Black respondents, 60% of Asian respondents, and 20% of Native American respondents reported that they have someone to take care of them if they get sick.

## **Fewer Latinos Have PPE in Homes**

51% of Latino respondents reported having PPE like masks and gloves in their homes. 74% of White respondents, 65% of Black respondents, 72% of Asian respondents, and 80% of Native American respondents reported they have PPE in their homes.

## **Extreme Worries about Access to Healthcare**

67% are worried that they or their family member won't get appropriate medical care during this time. 54% are concerned about having staff in their homes.

Specific concerns include:

- Not being allowed in hospital with family member
- Staff not trained, won't take time needed
- No communication support
- "Doctors won't talk to me as adult"

## **Most Experiencing Mental Health Effects from Isolation**

59% report experiencing effects on their mental health from isolation and the coronavirus pandemic.

Effects mentioned:

- Loneliness, anxiety, depression
- Increased challenges with coping Overwhelmed with worry and uncertainty Want routine to come back
- "Sad that I missed my prom"

## **Concern Extends to Loss of Income for Disability Families**

- 38% of households have experienced job loss in their household due to the coronavirus
- 38% are concerned about having enough money to pay rent or their mortgage
- 34% are concerned about having enough money to pay for food

## **Latinos More Likely to have Lost Jobs**

45% of Latino respondents reported someone in their household lost a job as a result of the coronavirus. Household job loss was reported by 34% of White respondents, 29% of Black respondents, 32% of Asian respondents, and 40% of Native American respondents.

### **Families of Color More Concerned about Paying Rent**

53% of Latino respondents, 48% of Asian respondents, 40% of Native American respondents, and 38% of Black respondents are concerned about paying rent due to the coronavirus. By contrast, 22% of White respondents are concerned about paying rent due to the coronavirus.

### **Families of Color More Concerned about Paying for Food due to Coronavirus**

51% of Latino respondents, 44% of Asian respondents, 20% of Native American respondents, and 54% of Black respondents are concerned about paying for food due to the coronavirus. By contrast, 12% of White respondents are concerned about paying for food due to the coronavirus.

### **40% of Asians Report Racial Discrimination**

40% of Asian respondents reported experiencing racial discrimination since the coronavirus outbreak began.

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June 9, 2020

**AGENDA ITEM 8.**

**POSSIBLE ACTION ITEM**

**STATE COUNCIL ON DEVELOPMENTAL DISABILITIES – SSDAC**

***Breakout Reports***

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Committee members will select a person from their breakout group to provide a 3 to 5-minute report on the work completed by their group. These reports could lead to action being taken on the Committee's work.

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June 9, 2020

**AGENDA ITEM 9.  
INFORMATIONAL ITEM**

**STATE COUNCIL ON DEVELOPMENTAL DISABILITIES – SSDAC**

***Next Meeting***

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SSDAC is currently scheduled to meet on October 2<sup>nd</sup>. This meeting is currently scheduled to take place in-person in Sacramento. However, given the current travel restrictions due to COVID-19, this may change. Committee and local advisory members will be notified if there are any changes.

If you wish to request an agenda item for the next meeting, please email your items to the Co-Chairs via Robin Maitino-Erben at [robin.maitino@scdd.ca.gov](mailto:robin.maitino@scdd.ca.gov).