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.

MEETING ID: 944 8800 3205
PASSWORD: 780149

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OR

JOIN BY TELECONFERENCE: (VOICE ONLY)
CALL IN NUMBER: 888-475-4499
MEETING ID: 944 8800 3205

DATE: September 25, 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
<table>
<thead>
<tr>
<th>Item 3.</th>
<th>WELCOME AND INTRODUCTIONS</th>
<th>Page 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Item 4.</td>
<td>PUBLIC COMMENTS</td>
<td>Page 4</td>
</tr>
<tr>
<td></td>
<td><em>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.</em></td>
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</tr>
<tr>
<td>Item 5.</td>
<td>APPROVAL OF JUNE 2020 MINUTES</td>
<td>Page 5</td>
</tr>
<tr>
<td>Item 6.</td>
<td>CO-CHAIR REPORT TO SSDAC</td>
<td>Page 10</td>
</tr>
<tr>
<td></td>
<td><em>Presented by: Maria Marquez and Rick Wood</em></td>
<td></td>
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<tr>
<td>Item 7.</td>
<td>LOCAL SDAC REPORTS</td>
<td>Page 11</td>
</tr>
<tr>
<td></td>
<td><em>Presented by: All Members and DDS</em></td>
<td></td>
</tr>
</tbody>
</table>

**LUNCH**

There will be a 30-minute lunch break following the Local SDAC Reports

| Item 8. | SSDAC REPORT ON BARRIERS TO IMPLEMENTING THE SELF-DETERMINATION PROGRAM – Next Steps | Page 12 |
|         | *Presented by: All* |
|         | a. What is the status of the report recommendations? |
|         | b. What can local advisory committees be doing to ensure the follow through of the recommendations? |

<table>
<thead>
<tr>
<th>Item 9.</th>
<th>NEXT MEETING AND ADJOURNMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>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 <a href="https://www.gov.ca.gov/wp-content/uploads/2020/03/3.17.20-N-29-20-EO.pdf">https://www.gov.ca.gov/wp-content/uploads/2020/03/3.17.20-N-29-20-EO.pdf</a> 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 <a href="mailto:robin.maitino@scdd.ca.gov">robin.maitino@scdd.ca.gov</a>. Please provide at least 3 business days prior to the meeting to allow adequate time to respond to all requests.</td>
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<tr>
<td>All times indicated and the order of business are approximate and subject to change.</td>
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</tbody>
</table>
September 25, 2020

AGENDA ITEM 3.
INFORMATIONAL ITEM

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES – SSDAC

Welcome and Introductions

Before turning the meeting over to members and others present for introductions, the Co-Chairs will go over virtual meeting etiquette for this meeting.
AGENDA ITEM 4.

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES – SSDAC

Public Comment
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.
AGENDA ITEM 5.
ACTION ITEM

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES – SSDAC

Approval of June 9, 2020 Minutes
The goal of this agenda item is to review and approve the meeting minutes from the last meeting.

Action Recommended
Approve the June 2020 minutes.

Attachment(s)
June 9, 2020 Minutes
1. **CALL TO ORDER**
   Chairperson Rick Wood (FA) called the meeting to order at 10:03 A.M.

2. **ESTABLISH QUORUM**
   A quorum was established.
3. **WELCOME/INTRODUCTIONS**
   Members and others introduced themselves as indicated.

4. **PUBLIC COMMENT**
   Member of the public Saniyyah Rasheed provided public comment stating her appreciation for the Governor’s announcement of a committee to address disparities in the African American Community. She added that racial disparities are present throughout the I/DD systems and it creates barriers to participation in the Self-Determination Program. She also stated that she was elected chair of the SGPRC SDAC and believes that she should be representing that local advisory committee in this meeting.

   Rob Lewis, the National Director of Business Development for GT Independence spoke about barriers that they have observed in the Self-Determination enrollment process, and urged the State Council and Regional Centers to put additional emphasis on the Self-Determination program and its benefits during the COVID-19 emergency.

   Speaking as the President of Disability Voices United (DVU), Judy Mark spoke to inform everyone that DVU has written budget language that has been adopted by the State Senate and Assembly, and is being used in negotiations with the Governor’s office to assist in getting everyone who is on the Self-Determination Program wait list by July 1st enrolled in the program. She asked that meeting attendees write to the Governor and to DDS to express their support. Judy also announced that DVU will be hosting weekly “SDP Connections” meetings via Zoom for anyone who is interested in learning about the Self-Determination program.

   Harvey Lapin provided public comment urging that we continue to adapt to new ways of doing business during the COVID-19 pandemic and work to get people off the waitlist and into the Self-Determination Program.

   Sonni Charness, founder of Guidelight Group spoke about her organization’s concerns regarding the barriers to implementation of the Self-Determination Program. She also spoke about how the use of technology during the COVID-19 emergency has assisted in providing services to clients.

5. **APPROVAL OF THE FEBRUARY 2020 MEETING MINUTES**
   It was moved/seconded (Landry/Orlina) and carried to approve the February 10, 2020 meeting minutes as amended. (Motion passed unanimously by acclamation [see page 1 for a list of voting members]).
6. **LOCAL SDAC REPORTS**
Chair Rick Wood requested that members who did not provide a report in the meeting packet share their reports at this time. He asked that committee members share any updates or changes to their reports. Members provided updates to their participant data. A link to the HRC report was provided in the chat box, and announcements were made regarding RCEB’s plans for the use of funds from DDS.

There was discussion about the need to collect data on the ethnicities of program participants in order to stay informed of any racial disparities.

Members discussed the importance of Self-Determination Committee members writing their own reports to ensure that they are providing appropriate oversight over the Regional Centers.

Jim Knight from DDS provided a report to the committee that included information about changes to the background check process, funding to Regional Centers, and survey results from those who have chosen not to participate in the Self-Determination Program.

7. **BREAKOUT: BARRIERS TO SELF-DETERMINATION IN THE AGE OF COVID-19**
Workgroups comprised of committee members, regional center staff and DDS staff broke into four groups to continue work on the February draft Barriers to Implementation report. The purpose of the workgroups was to arrive at consensus on the recommendations to overcome the barriers. Three additional groups containing members of the public that were led by Committee members also broke into workgroups to provide recommendations on each barrier identified in the draft report.

8. **BREAKOUT REPORTS**
Workgroup leaders from each of the seven (7) workgroups provided a summary on the group’s outcomes. Each leader committed to putting their findings in writing and providing them to staff and the co-chairs to synthesize and put into a final report that would be distributed to the Legislature, DDS, Regional Centers and SCDD.
It was moved/seconded (Mark/Nutt) and carried to adopt the recommendations made by breakout groups and incorporate them into the draft report, provided the recommendations do not contradict one another. To ensure this, it was further moved that the co-chairs synthesize and summarize the information to incorporate into a final draft report to be distributed to the Legislature, DDS, Regional Centers and SCDD. Passed by unanimous consent. (Motion passed unanimously by acclamation [see page 1 for a list of voting members]).

9. NEXT MEETING
Co-Chair Rick Wood announced that October 2, 2020 was the next scheduled meeting date. Committee members voiced concern about waiting so long to meet and requested to meet every other month via Zoom. Executive Director Aaron Carruthers stated that the Council did not have the resources to meet 6 times a year.

It was moved/seconded (Mark/Chan-Rapp) and carried to meet every two months for the next year, contingent upon staff availability. (Not Present: Cooley; Opposed: Taylor; Abstain: Orlina and Nutt; All others present voted in favor. [See page 1 for a list of voting members].)

10. ADJOURN
The meeting was adjourned at 2:47 P.M.
AGENDA ITEM 6.
INFORMATIONAL ITEM

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES – SSDAC

Co-Chair Report to SSDAC

Co-Chairs will provide a report on SSDAC related activities since the last meeting.
AGENDA ITEM 7.
INFORMATIONAL ITEM

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES – SSDAC

*Local SDAC Report*

Committee members will provide a brief report on the status of program implementation at their regional centers. Committee members that submit written reports by September 17th will have their reports emailed and posted prior to the meeting.

DDS has also been invited to provide relevant updates.
AGENDA ITEM 8.
POTENTIAL ACTION ITEM

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES – SSDAC

SSDAC Report on Barriers to Implementing the Self-Determination Program – Next Steps

Committee members will discuss the progress made on of the recommendations provided within the report and what the local advisory committees can be doing to ensure the follow through of the recommendations. To assist members with this discussion, the recommendations are attached and grouped by agency/entity responsible.

Also attached are copies of the full report in both English and Spanish. Members are encouraged to share both versions of the report with their community.

Attachments

• Report Recommendations Grouped by Agency/Entity Responsible
• SSDAC Report: Barriers to Implementing the Self-Determination Program (English Version)
• SSDAC Report: Barriers to Implementing the Self-Determination Program (Spanish Version)
Report Recommendations – Grouped by Responsibility

**Barriers Reported**

1. Delay in implementation of the SDP.
2. Lack of guidance by DDS to regional centers and consumers, resulting in inconsistent implementation of the SDP across the regional center system.
3. Lack of trainings for regional center’s staff, participants and families.
4. Lack of trainings for, and development of person-centered planners, fiscal management services, independent facilitators and service providers.

**Responsibility**

Local Advisory Committees (Local SDAC)

1. DDS should establish benchmarks for implementation of the SDP by regional centers. **LACs** should monitor progress and attainment of established goals *(BARRIER 1)*
2. LACs should consult with regional centers on best practices and share them with the SSDAC, which should highlight “beacons,” those regional centers which are performing well. *(BARRIER 2)*
3. DDS should develop required information meetings and orientations in short, plain-language format, in English and Spanish languages. Explanations of the roles of financial management service and independent facilitator should be simple and presented in plain-language format. The SSDAC should provide feedback to LACs and regional centers on best practices and training models. Orientations should include **LAC members** as active participants. *(BARRIER 3)*
4. Regional centers should conduct trainings and orientations at multiple times and places, including virtual presentations, in English and Spanish. Use of technology when available, combined with individual family and small-group meetings, should be initiated in order to reach all potential participants. **LAC members** should not only participate in orientations and trainings but should lead them. The focus of all trainings should be on purpose vs. process, including an emphasis on “who is in charge” and encouragement of individuality and creativity in the development of person-centered plans. *(BARRIER 3)*
5. Regional centers should be required to follow up with all consumers and families who have participated in orientations. **LACs should** invite all SDP participants to committee meetings. *(BARRIER 3)*
6. Regional centers should inform and educate current, vendored service providers about the SDP, and should recruit non-vendored providers to offer services to SDP participants. **LACs should** invite providers to attend their committee meetings in order to inform them of opportunities to provide services and supports. *(BARRIER 4)*
Statewide Self-Determination Advisory Committee (SSDAC)
1. The SSDAC should share models of success and encourage LACs to apply lessons learned to local implementation. (BARRIER 1)
2. DDS should timely share the results of the survey of those who have disenrolled from the SDP to discover and understand the rationale for disenrollment with LACs and SSDAC. Once received, the SSDAC should analyze the results and make recommendations to increase participation in the SDP. (BARRIER 1)
3. DDS should develop required information meetings and orientations in short, plain-language format, in English and Spanish languages. Explanations of the roles of financial management service and independent facilitator should be simple and presented in plain-language format. The SSDAC should provide feedback to LACs and regional centers on best practices and training models. Orientations should include LAC members as active participants. (BARRIER 3)

Department of Developmental Services
1. DDS and regional centers should provide monthly reports to LACs which include the number of SDP participants, the pace of enrollment, orientation, development of person-centered plans and budgets, and transition into the program which are broken down by regional center, race/ethnicity, and the number of previously-interested individuals and families who have disenrolled from the SDP. (BARRIER 1)
2. DDS should timely share the results of the survey of those who have disenrolled from the SDP to discover and understand the rationale for disenrollment with LACs and SSDAC. Once received, the SSDAC should analyze the results and make recommendations to increase participation in the SDP. (BARRIER 1)
3. DDS should establish a goal for participants to transition to the SDP within six-months from the date of selection. (BARRIER 1)
4. DDS should establish benchmarks for implementation of the SDP by regional centers. LACs should monitor progress and attainment of established goals (BARRIER 1)
5. DDS should issue clear and consistent guidance and directives to regional centers and Local Advisory Committees, including in the following areas: orientation, person-centered planning, use of generic resources, development of spending plan and budget, and trainings. (BARRIER 2)
6. DDS should identify and hire a “champion” within DDS dedicated to coordinating the implementation of the of SDP with regional centers. (BARRIER 2)
7. DDS should establish and update FAQs on its website. (BARRIER 2)
8. DDS and regional centers should draw on the experience of self-determination pilot projects. (BARRIER 2)
9. DDS should monitor implementation of the SDP by regional centers for underserved participants and those with prior unmet needs in order to avoid racial and ethnic disparities. (BARRIER 2)
10. DDS should prioritize systemic oversight and require strict accountability of regional centers. (BARRIER 2)

11. The goal of DDS and regional centers should be to establish continuity across all SDP systems. (BARRIER 2)

12. DDS should develop mandatory, consistent training regimens for regional center staff, and should provide timelines for and oversight of trainings and require accountability from regional centers. Trainings should include participation by LAC members. Trainings should include a focus on the spending plan and budget processes in order to avoid confusion and inconsistent communication with participants and families. (BARRIER 3)

13. DDS should develop required information meetings and orientations in short, plain-language format, in English and Spanish languages. Explanations of the roles of financial management service and independent facilitator should be simple and presented in plain-language format. The SSDAC should provide feedback to LACs and regional centers on best practices and training models. Orientations should include LAC members as active participants. (BARRIER 3)

14. DDS should provide a clear definition of the term, “unmet needs” for systemic application. (BARRIER 2)

15. DDS should develop training materials for person-centered planners and independent facilitators. However, regional centers should not be restricted from developing additional training materials specific to the needs of their constituents. Regional centers should conduct outreach to potential person-centered planners and conduct trainings for interested persons and entities. Regional centers should provide opportunities for participants to meet and engage with independent facilitators. This should not be left to the “marketplace.” As a marketplace develops, regional centers should not limit outreach to “certified” independent facilitators which could limit choice of independent facilitators by participants. (BARRIER 4)

16. DDS should develop a plain-language explanation of the role of the FMS. DDS should provide direct oversight of FMS’ and require accountability, and should streamline the guest vendorship process for FMS’ in order to increase FMS choices for participants. DDS should publish on its website accurate information about FMS’ who are available to provide services in each regional center. Regional centers must timely distribute funds to FMS’ so as not to delay payment to providers of services and supports, and to meet participants’ immediate needs or respond to crises. (BARRIER 4)

Regional Centers
1. DDS and regional centers should provide monthly reports to LACs which include the number of SDP participants, the pace of enrollment, orientation, development of person-centered plans and budgets, and transition into the program which are broken down by regional center, race/ethnicity, and the
number of previously-interested individuals and families who have disenrolled from the SDP. (BARRIER 1)

2. Regional centers should develop an effective means of facilitating the dissemination of DDS guidance and directives to regional center staff, whether by the establishment of “dedicated” SDP service coordinators, or through cross-training all service coordinators. (BARRIER 2)

3. Regional centers should utilize available funding for individuals’ initial person-centered planning process. (BARRIER 2)

4. DDS and regional centers should draw on the experience of self-determination pilot projects. (BARRIER 2)

5. The goal of DDS and regional centers should be to establish continuity across all SDP systems. (BARRIER 2)

6. Regional centers should conduct trainings and orientations at multiple times and places, including virtual presentations, in English and Spanish. Use of technology when available, combined with individual family and small-group meetings, should be initiated in order to reach all potential participants. LAC members should not only participate in orientations and trainings but should lead them. The focus of all trainings should be on purpose vs. process, including an emphasis on “who is in charge” and encouragement of individuality and creativity in the development of person-centered plans. (BARRIER 3)

7. Regional centers should be required to follow up with all consumers and families who have participated in orientations. LACs should invite all SDP participants to committee meetings. (BARRIER 3)

8. DDS should develop training materials for person-centered planners and independent facilitators. However, regional centers should not be restricted from developing additional training materials specific to the needs of their constituents. Regional centers should conduct outreach to potential person-centered planners and conduct trainings for interested persons and entities. Regional centers should provide opportunities for participants to meet and engage with independent facilitators. This should not be left to the “marketplace.” As a marketplace develops, regional centers should not limit outreach to “certified” independent facilitators which could limit choice of independent facilitators by participants. (BARRIER 4)

9. Regional centers should inform and educate current, vendored service providers about the SDP, and should recruit non-vendored providers to offer services to SDP participants. LACs should invite providers to attend their committee meetings in order to inform them of opportunities to provide services and supports. (BARRIER 4)
A STATEWIDE SELF-DETERMINATION ADVISORY COMMITTEE
REPORT ON THE BARRIERS TO IMPLEMENTING
THE SELF-DETERMINATION PROGRAM

AUGUST 10, 2020
# Table of Contents

Introduction ........................................................................................................................................... 1
Summary of Findings ............................................................................................................................. 1
  Barrier 1: Delay in Implementation of the SDP .............................................................................. 2
Recommendations ............................................................................................................................... 2
  Barrier 2: Lack of Guidance by DDS to Regional Centers and Consumers ......................... 3
Recommendations ............................................................................................................................... 3
  Barrier 3: Lack of Trainings for Regional Center Staff, Participants & Families ............ 4
Recommendations ............................................................................................................................... 4
  Barrier 4: Lack of Trainings for, and Development of Person-Centered Planners, Fiscal Management Services, Independent Facilitators & Service Providers ........... 5
Recommendations ............................................................................................................................... 5
Conclusion: Achievable Outcomes ...................................................................................................... 6
REPORT ON BARRIERS TO IMPLEMENTATION OF THE SELF-DETERMINATION PROGRAM AND RECOMMENDATIONS TO OVERCOME THEM

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

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

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

1. Delay in implementation of the SDP.
2. Lack of guidance by DDS to regional centers and consumers, resulting in inconsistent implementation of the SDP across the regional center system.
3. Lack of trainings for regional center’s staff, participants and families.
4. Lack of trainings for, and development of person-centered planners, fiscal management services, independent facilitators and service providers.
Barrier 1: Delay in Implementation of the SDP
The excitement about an anticipated new and different means of delivery of services and supports to regional center consumers in 2013 has been tempered by a nearly five-year delay in seeking and obtaining approval of its federal waiver application. While DDS should be commended for shepherding the waiver application through a hard and complicated process, this delay has resulted in a loss of momentum for and interest in the SDP by many individuals and families. The inability to timely move the program forward has left many regional center staff, LAC members, and consumers and families with low enthusiasm for the SDP. This has become worse due to COVID-19. The loss of momentum has impacted systemic change in the philosophy, culture, attitude and practice of self-determination. In many instances, potential participants have expressed a lack of understanding of the program, fear of change, discouragement, and a lack of hope. A “paradigm shift” in which people believe that they have substantial freedom of choice and the ability to control their own lives has not yet occurred.

Recommendations
- DDS and regional centers should provide monthly reports to LACs which include the number of SDP participants, the pace of enrollment, orientation, development of person-centered plans and budgets, and transition into the program which are broken down by regional center, race/ethnicity, and the number of previously-interested individuals and families who have disenrolled from the SDP.
- DDS should timely share the results of the survey of those who have disenrolled from the SDP to discover and understand the rationale for disenrollment with LACs and SSDAC. Once received, the SSDAC should analyze the results and make recommendations to increase participation in the SDP.
- DDS should establish a goal for participants to transition to the SDP within six-months from the date of selection.
- DDS should establish benchmarks for implementation of the SDP by regional centers. LACs should monitor progress and attainment of established goals.
- The SSDAC should share models of success and encourage LACs to apply lessons learned to local implementation.
**Barrier 2: Lack of Guidance by DDS to Regional Centers and Consumers**

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

**Recommendations**

- DDS should issue clear and consistent guidance and directives to regional centers and Local Advisory Committees, including in the following areas: orientation, person-centered planning, use of generic resources, development of spending plan and budget, and trainings.
- DDS should identify and hire a “champion” within DDS dedicated to coordinating the implementation of the SDP with regional centers.
- DDS should establish and update FAQs on its website.
- DDS and regional centers should draw on the experience of self-determination pilot projects.
- Regional centers should develop an effective means of facilitating the dissemination of DDS guidance and directives to regional center staff, whether by the establishment of “dedicated” SDP service coordinators, or through cross-training all service coordinators.
- DDS should provide a clear definition of the term, “unmet needs” for systemic application.
- Regional centers should utilize available funding for individuals’ initial person-centered planning process.
- LACs should consult with regional centers on best practices and share them with the SSDAC, which should highlight “beacons,” those regional centers which are performing well.
- DDS should monitor implementation of the SDP by regional centers for underserved participants and those with prior unmet needs in order to avoid racial and ethnic disparities.
- DDS should prioritize systemic oversight and require strict accountability of regional centers.
- The goal of DDS and regional centers should be to establish continuity across all SDP systems.
Barrier 3: Lack of Trainings for Regional Center Staff, Participants & Families

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

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

Recommendations

- DDS should develop mandatory, consistent training regimens for regional center staff, and should provide timelines for and oversight of trainings and require accountability from regional centers. Trainings should include participation by LAC members. Trainings should include a focus on the spending plan and budget processes in order to avoid confusion and inconsistent communication with participants and families.
- DDS should develop required information meetings and orientations in short, plain-language format, in English and Spanish languages. Explanations of the roles of financial management service and independent facilitator should be simple and presented in plain-language format. The SSDAC should provide feedback to LACs and regional centers on best practices and training models. Orientations should include LAC members as active participants.
- Regional centers should conduct trainings and orientations at multiple times and places, including virtual presentations, in English and Spanish. Use of technology when available, combined with individual family and small-group meetings, should be initiated in order to reach all potential participants. LAC members should not only participate in orientations and trainings but should lead them. The focus of all trainings should be on purpose vs. process, including an emphasis on “who is in charge” and encouragement of individuality and creativity in the development of person-centered plans.
- Regional centers should be required to follow up with all consumers and families who have participated in orientations. LACs should invite all SDP participants to committee meetings.
Barrier 4: Lack of Trainings for, and Development of Person-Centered Planners, Fiscal Management Services, Independent Facilitators and Service Providers

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

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

Recommendations

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

**Conclusion: Achievable Outcomes**

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

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

This is not complicated. The SDP structure and systems are in place. The SSDAC and its LAC members are committed to collaborating with DDS, State Council on Developmental Disabilities and regional centers to overcome the barriers to implementation in advance of June 2021 and thereafter. It is only with such collaboration; will the program achieve the results which were intended by the passage and signing of SB 468 in 2013.
UN COMITÉ ASESOR DE AUTODETERMINACIÓN A NIVEL ESTATAL
REPORTE SOBRE LAS BARRERAS PARA IMPLEMENTAR
EL PROGRAMA DE AUTODETERMINACIÓN

10 DE AGOSTO DE 2020
Tabla de contenidos

Introducción .................................................................................................................................................. 1
Resumen de hallazgos .................................................................................................................................. 1
  Barrera 1: Retraso en la implementación del SDP .................................................................................. 2
Recomendaciones .......................................................................................................................................... 2
  Barrera 2: Falta de orientación por parte de DDS para los centros regionales y los consumidores ........................................................................................................................................ 3
Recomendaciones .......................................................................................................................................... 3
  Barrera 3: Falta de entrenamiento para el personal del centro regional, los participantes y familias .................................................................................................................................................. 4
Recomendaciones .......................................................................................................................................... 4
  Barrera 4: Falta de entrenamiento y desarrollo para los planeadores enfocados en las personas, servicios de administración fiscal, facilitadores independientes y proveedores de servicios .................................................................................................................................. 5
Recomendaciones .......................................................................................................................................... 5
Conclusión: Resultados obtenibles ............................................................................................................ 6
Introducción
El 7 de octubre de 2013, se creó un Programa Estatal de Autodeterminación (SDP, por sus siglas en inglés) cuando el Gobernador Jerry Brown firmó el Proyecto de Ley del Senado (SB, por sus siglas en inglés) 468. Este programa está basado en proyectos piloto de autodeterminación exitosos que duraron varios años, los cuales les dieron a los individuos con discapacidades del desarrollo una planeación auténtica enfocada en las personas, elecciones y control sobre sus servicios y apoyo, además de mejores resultados, con posibles ahorros de costo a largo plazo. La ley requería que California buscase financiamiento federal para el programa presentándole una solicitud de exención al Departamento de Servicios de Desarrollo (DDS, por sus siglas en inglés), lo cual fue desarrollado en un período de varios años y presentado en marzo de 2018. El gobierno federal aprobó la solicitud de exención el 7 de junio de 2018, lo cual inició un período de establecimiento gradual de tres años en el cual 2500 consumidores interesados de centros regionales fueron seleccionados al azar para participar. El propósito del período de establecimiento gradual incluía la oportunidad de implementar el SDP antes de que su expansión se volviera disponible para todos los consumidores en los centros regionales el 7 de junio de 2021.

La membresía del Comité Asesor de Autodeterminación a Nivel Estatal (SSDAC, por sus siglas en inglés) consiste de los presidentes o representantes de los 21 Comités Asesores Locales (LAC, por sus siglas en inglés) de los centros regionales y un copresidente estatal nombrado por el Consejo Estatal de Discapacidades del Desarrollo. El mandato legislativo del LAC debe proporcionar supervisión y orientación sobre la implementación del SDP. En agosto de 2020, un poco más de 200 consumidores de centros regionales han hecho la transición al SDP, de los cuales casi la mitad son exparticipantes en los proyectos piloto de autodeterminación de 20 años. El SSDAC ha participado en un ejercicio para identificar las barreras para la implementación del SDP en conjunto con el personal del centro regional y los miembros interesados/involucrados de la comunidad de discapacidades del desarrollo y hace recomendaciones sobre cómo superarlas.

Resumen de hallazgos
El SSDAC descubrió que las barreras significativas para la implementación del SDP caen en una de las siguientes cuatro categorías, las cuales no lo incluyen todo:

1. Retraso en la implementación del SDP.

2. Falta de orientación por parte del DDS para los centros regionales y consumidores, lo cual resulta en la implementación inconsistente del SDP en el sistema de centros regionales.

3. Falta de entrenamiento para el personal del centro regional, los participantes y familias.

4. Falta de entrenamiento y desarrollo para los planeadores enfocados en las personas, servicios de administración fiscal, facilitadores independientes y proveedores de servicios.

10 de agosto de 2020
Barrera 1: Retraso en la implementación del SDP
La emoción sobre un medio anticipado de prestación de servicios y apoyo nuevo y diferente para los consumidores del centro regional en el año 2013 ha sido templada por un retraso de casi cinco años en la búsqueda y obtención de aprobación de su solicitud federal de exención. Si bien el DDS debería ser elogiado por guiar la solicitud de exención a lo largo de un proceso difícil y complicado, este retraso ha resultado en una pérdida de ímpetu e interés en el SDP por parte de muchos individuos y familias. La incapacidad de hacer avanzar el programa a tiempo ha dejado a muchos miembros del personal del centro regional, miembros de LAC, consumidores y familias con poco entusiasmo por el SDP. Esto ha empeorado debido al COVID-19. La pérdida de ímpetu ha afectado el cambio sistemático en la filosofía, cultura, actitud y práctica de la autodeterminación. En muchos casos, los posibles participantes han expresado una falta de comprensión del programa, temor al cambio, desánimo y falta de esperanza. Aún no ha ocurrido un “cambio de paradigma” en el cual las personas creen que tienen una libertad de elección sustancial y la capacidad de controlar sus propias vidas.

Recomendaciones
- El DDS y los centros regionales deben proporcionarle reportes mensuales a los LAC, los cuales incluyen el número de participantes en el SDP, el ritmo de inscripción, la orientación, desarrollo de planes enfocados en las personas y presupuestos, y la transición al programa, lo cual es desglosado por centro regional, raza/étnicidad y el número de individuos y familias interesados previamente que se han dado de baja del SDP.
- El DDS debería compartir oportunamente los resultados de la encuesta realizada a quienes se han dado de baja del SDP para determinar y entender las razones para la dada de baja con los LAC y el SSDAC. Cuando sean recibidos, el SSDAC debe analizar los resultados y hacer recomendaciones para aumentar la participación en el SDP.
- El DDS debe establecer una meta para que los participantes hagan la transición al SDP dentro de seis meses de la fecha de selección.
- El DDS debe establecer puntos de referencia para la implementación del SDP por parte de los centros regionales. Los LAC deben monitorear el progreso y la obtención de las metas establecidas.
- El SSDAC debe compartir modelos de éxito y animar a los LAC a aplicar las lecciones aprendidas a la implementación local.
**Barrera 2: Falta de orientación por parte del DDS para los centros regionales y los consumidores**

Un tema común entre los miembros del SSDAC es que los centros regionales no cuentan con lineamientos consistentes para la implementación del SDP. El DDS ha sido lento en la emisión de la orientación y las directivas para los centros regionales y los participantes del SDP. A pesar de los esfuerzos del DDS, muchos participantes y personal del centro regional no han entendido la mecánica de la autodeterminación.

Una falta de orientación lleva inevitablemente a que el DDS tenga que reaccionar a problemas emergentes según el caso, lo cual conlleva a disparidades geográficas en la implementación. Las comunidades desatendidas se enfrentan a obstáculos adicionales para la autodeterminación, y hay evidencia de que las disparidades étnicas y raciales son perpetuadas por el SDP. Los procesos inconsistentes dentro del SDP han sido desarrollados por los centros regionales que están acostumbrados a las reglas, formularios y procedimientos y, por lo tanto, no se han ajustado al nuevo nivel normal de autodeterminación en el cual los participantes están “a cargo”. Si bien la flexibilidad y la creatividad son sellos distintivos de la autodeterminación, la “burocratización” del SDP ha desanimado a los posibles participantes, lo cual conlleva a altas tasas de deserción. El DDS no ha proporcionado la supervisión necesaria y la responsabilidad requerida de los centros regionales, algunos de los cuales están implementando el SDP de forma proactiva y otros que se están resistiendo abierta o encubiertamente a su implementación. El resultado es una inconsistencia general del lanzamiento del período de incorporación gradual.

**Recomendaciones**

- El DDS debe emitir orientación clara y consistente además de lineamientos para los centros regionales y los Comités Asesores Locales, incluyendo en las siguientes áreas: orientación, planeación enfocada en las personas, uso de recursos genéricos, desarrollo de planes de gastos y presupuestos, y entrenamientos.
- El DDS debe identificar y contratar a un “campeón” dentro del DDS que esté dedicado a coordinar la implementación del SDP con los centros regionales.
- El DDS debe establecer y actualizar las preguntas frecuentes en su sitio web.
- El DDS y los centros regionales deben aprovechar la experiencia de los proyectos piloto de autodeterminación.
- Los centros regionales deben desarrollar un medio efectivo para facilitar la diseminación de la orientación del DDS y las directivas para el personal del centro regional, ya sea por medio del establecimiento de coordinadores de servicio “dedicados” del SDP o a través de entrenamiento cruzado con todos los coordinadores de servicio.
- El DDS debe proporcionar una definición clara del término “necesidades insatisfechas” para la aplicación sistémica.
- Los centros regionales deben usar los fondos disponibles para el proceso inicial de planeación enfocado en la persona.
- Los LAC deben consultar a los centros regionales sobre las mejores prácticas y compartirlas con el SSDAC, el cual debería resaltar los “modelos”, los cuales son los centros regionales que están desempeñándose bien.
- El DDS debe monitorear la implementación del SDP por parte de los centros regionales para los participantes desatendidos y quienes tienen necesidades insatisfechas previas para evitar las disparidades raciales y étnicas.
- El DDS debe priorizar la supervisión sistémica y debe requerir una responsabilidad estricta de los centros regionales.
- La meta del DDS y de los centros regionales debe ser establecer continuidad a lo largo de todos los sistemas SDP.
Falta de entrenamiento para el personal del centro regional, los participantes y familias

El DDS emprendió un esfuerzo para presentar los principios de la autodeterminación y los procesos del SDP en otoño de 2018, promoviendo y realizando seis sesiones separadas de orientación/entrenamiento de un día completo a lo largo del estado, en el cual participó el personal del centro regional. Si bien los entrenamientos no fueron exhaustivos, fueron bien recibidos por quienes asistieron. Sin embargo, no ha habido un mandato que diga que el personal del centro regional deba asistir a orientación, el resultado de la cual es que muchos coordinadores de servicio saben muy poco sobre el SDP, incluso si ocupan una posición de primera línea en la implementación. En algunos casos, los coordinadores de servicio no comprendieron que los participantes del SDP podían seleccionar a un facilitador independiente para que realizara la planeación enfocada en la persona.

El personal del centro regional ha tenido dificultad para entender el proceso de presupuesto. Algunos coordinadores de servicio han declarado que el SDP es solo para quienes tienen requisitos no complicados; mientras que otros ven al SDP como aplicable solo para quienes tienen planes complicados y presupuestos altos. No hay consistencia sistémica en la presentación de la oportunidad SDP para los consumidores y las familias.

De forma similar, el DDS ha animado a los centros regionales a desarrollar sus propias orientaciones y entrenamientos para los posibles participantes. Si bien es una buena meta personalizar el SDP a las circunscripciones específicas de cada centro regional, esto ha llevado a una variedad de estrategias y materiales de orientación y entrenamiento. Han surgido confusión y malentendidos debido, en algunos casos, a una falta de entrenamientos no complicados con lenguaje simple para los consumidores y sus familias. Ha habido inconsistencias entre los centros regionales en el monitoreo de los participantes después de la orientación. Esto ha resultado en tasas de deserción inaceptables de quienes habían expresado interés en el SDP previamente.

Recomendaciones

- El DDS debería desarrollar regímenes obligatorios y consistentes de entrenamiento para el personal de los centros regionales y debe proporcionar líneas de tiempo y supervisión de los entrenamientos, además de requerir la rendición de cuentas de los centros regionales. Los entrenamientos deberían incluir la participación de miembros de los LAC. Los entrenamientos deberían estar enfocados en el plan de gastos y los procesos de presupuestación para evitar confusiones e inconsistencia en la comunicación con los participantes y las familias.
- El DDS debe desarrollar las reuniones de información requeridas y orientaciones en un formato corto con lenguaje simple, en inglés y español. Las explicaciones de los papeles del servicio de administración financiera y de los facilitadores independientes deberían ser simples y presentadas en un formato con lenguaje simple. El SSDAC debe proporcionar retroalimentación para los LAC y centros regionales sobre las mejores prácticas y modelos de entrenamiento. Las orientaciones deberían incluir a los miembros de los LAC como participantes activos.
- Los centros regionales deben llevar a cabo entrenamientos y orientaciones en varios lugares y momentos, incluyendo presentaciones virtuales en inglés y español. El uso de la tecnología cuando está disponible, combinado con reuniones individuales familiares y de grupos pequeños debe ser iniciado para poder llegar a todos los posibles participantes. Los miembros de los LAC no solo deben participar en orientaciones y entrenamientos, sino que deben liderarlos. El enfoque de todos los entrenamientos debe estar en el propósito vs. el proceso, incluyendo un énfasis en “quién está a cargo” y fomento de la individualidad y creatividad en el desarrollo de planes enfocados en las personas.
- Los centros regionales deberían tener que darle seguimiento a todos los consumidores y familias que han participado en las orientaciones. Los LAC deben invitar a todos los participantes del SDP a las reuniones del comité.

10 de agosto de 2020
Barrera 4: Falta de entrenamiento y desarrollo para los planeadores enfocados en las personas, servicios de administración fiscal, facilitadores independientes y proveedores de servicios

El éxito del SDP depende de la habilidad de los participantes para ubicar a proveedores en quienes puedan confiar. El sello distintivo de los pilotos de autodeterminación fue el desarrollo de redes de proveedores que trabajaron sin problemas para ayudar a los participantes en el desarrollo de planes enfocados en las personas, creación de presupuestos, administración de fondos, ubicación de servicios y apoyos disponibles y coordinación con personal del centro regional.

Han surgido barreras durante el período de lanzamiento debido a la incapacidad de los participantes para encontrar facilitadores independientes entrenados, un proceso de venta lento para los FMS y una falta de proveedores de servicios tradicionales que entiendan la oportunidad de prestar servicios y apoyo fuera del sistema de ventas tradicional. Hay evidencias de que algunos FMS vendidos han elegido no participar en el SDP a nivel estatal o han restringido la aceptación de participantes dependiendo la complexidad de los planes.

No hay materiales de entrenamiento o compromiso con personas interesadas en convertirse en planeadores enfocados en las personas y facilitadores independientes, lo cual resulta en inconsistencias en el desarrollo de planes.

Se espera que, conforme aumente el número de participantes, se desarrolle una “profesión” de facilitador independiente. Sin embargo, eso aún no ha ocurrido, lo cual resulta en una dependencia excesiva por parte de los participantes en los coordinadores de servicio de los centros regionales para desarrollar planes y presupuestos enfocados en las personas. Los únicos vendedores requeridos en el SDP son los FMS. Los requisitos para ventas del estado de las organizaciones FMS son pesados, limitando el número y la variedad de los FMS disponibles para los participantes. En algunos casos, los FMS han experimentado retrasos en la recepción oportuna de fondos de los centros regionales para pagar servicio y asistencia. Los proveedores de servicios que proporcionan servicios y apoyos en el sistema de entrega tradicional no están familiarizados y les falta conocimiento del SDP. Esto afecta la creatividad e individualidad de los planes enfocados en las personas.

Recomendaciones

- El DDS debe desarrollar material de entrenamiento para los planeadores enfocados en las personas y los facilitadores independientes. Sin embargo, los centros regionales no deben estar restringidos del desarrollo de materiales adicionales de entrenamiento que sean específicos para las necesidades de sus constituyentes. Los centros regionales deben divulgar la información a los posibles planeadores enfocados en las personas y deben llevar a cabo entrenamiento para las personas y entidades interesadas. Los centros regionales deben prestar oportunidades para que los participantes conozcan y participen con los facilitadores independientes. Esto no debería ser dejado en manos del “mercado”.

Conforme el mercado se desarrolla, los centros regionales no deben limitar su divulgación a los facilitadores independientes “certificados”, lo cual podría limitar la elección de facilitadores independientes por parte de los participantes.

- El DDS debe desarrollar una explicación del papel del FMS usando lenguaje simple. El DDS debe proporcionar supervisión directa de los FMS y requerir rendición de cuentas, además de optimizar el proceso de venta de los huéspedes para los FMS y así aumentar las opciones de FMS para los participantes. El DDS debe publicar información exacta en su sitio web sobre los FMS que están disponibles para ofrecer servicios en cada centro regional. Los centros regionales deben distribuir los fondos oportunamente para los FMS para no retrasar el pago a los proveedores de servicios y apoyos y para satisfacer las necesidades inmediatas de los participantes o responder a las crisis.
Los centros regionales deben informar y educar a los proveedores de servicios actuales sobre el SDP y deben reclutar a proveedores no vendidos para ofrecer servicios para los participantes del SDP. Los LAC deben invitar a los proveedores para que asistan a sus reuniones de comité para informarles sobre las oportunidades de prestar servicios y apoyo.

Conclusión: Resultados obtenibles
El SDP está basado en los principios de libertad, autoridad, apoyo, responsabilidad y confirmación. La autodeterminación no es nueva. El programa viene de proyectos piloto exitosos de 20 años en California. La oportunidad de proporcionar elecciones auténticas y significativas para los individuos y control sobre sus servicios y apoyo, y por lo tanto sus vidas, producirá mejores resultados y probablemente ahorros de costos a largo plazo. El SDP está aún en su infancia.

El propósito del período de implementación gradual de tres años es probar los procesos, aprender de los errores comunes e identificar las mejores prácticas y aplicarlas sistemáticamente conforme el SDP va a nivel estatal en el 2021. El DDS, los centros regionales, el SSDAC, los LAC, los defensores, participantes y las familias tienen un papel que jugar en el éxito del programa. La identificación de barreras para la implementación no debería ser interpretada como una imputación de autodeterminación o como un fracaso del SDP. En lugar de eso, después de un análisis riguroso de las barreras, las recomendaciones en este reporte deben superar las barreras para poder cumplir con los objetivos del SDP. El SSDAC ha concluido que, en parte, el tamaño pequeño de los participantes del SDP seleccionados durante el período de implementación gradual es por sí mismo una barrera. Se espera que se supere a partir de 2021 conforme el programa se vuelve disponible para todos los consumidores de los centros regionales y las familias que están interesadas en el SDP, el cual es un paso positivo hacia la autodeterminación.

 Esto no es complicado. La estructura del SDP y los sistemas se han establecido. El SSDAC y sus miembros de los LAC están comprometidos a colaborar con el DDS, el consejo estatal sobre discapacidades del desarrollo y los centros regionales para superar las barreras a la implementación antes de junio de 2021 y aún después. Es solo con dicha colaboración que el programa logrará los resultados que se pretendieron al firmar el Proyecto de Ley del Senado 468 en el año 2013.