

State Council on Developmental Disabilities



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May 23, 2025

Mr. Pete Cervinka, Director Department of Developmental Services P.O. Box 944202 Sacramento, CA 94244-2020

RE SSDAC TOWN HALL; FEEDBACK AND RECOMMENDATIONS

Dear Director Cervinka:

The State Council on Developmental Disabilities (SCDD) and the Statewide Self-Determination Advisory Committee (SSDAC) would like to thank the Department of Developmental Services (DDS/Department) for its attendance at the SSDAC Town Hall event on December 4th, 2024. SCDD has gathered the information shared during the event and is pleased to present the feedback (enclosed as an attachment).

The enclosed report reflects Town Hall participants' experiences with the SDP. The report also includes recommendations generated from the public comments provided by Town Hall participants. The SSDAC and SCDD request that the Department consider these recommendations carefully and would like to state that the comments provided do not necessarily reflect those of SCDD or the SSDAC.

In closing, the SSDAC requests that the Department agendize the Town Hall event findings for its next DDS SDP Advisory Committee meeting. The SSDAC would also like to invite DDS to its next meeting (June 24, 2025) to discuss next steps. SCDD and the SSDAC appreciate the Department's willingness to collaborate in addressing concerns expressed by Self-Determination Program (SDP) participants.

Mr. Pete Cervinka, Director Page 2 May 23, 2025

Should you have any questions about the content of the enclosed report, please feel free to contact us at your convenience.

Kindest Regards,

Rick Wood, Co-Chair Statewide Self-Determination Advisory Committee (SSDAC)

Nestor Nieves, Co-Chair Statewide Self-Determination Advisory Committee (SSDAC)

Nestor Nieres

Principles of Self-Determination

C A L I F O R N I A

SCDD

State Council on Developmental Disabilities

Insights from the December 4, 2024, Town Hall and Recommendations for Future Success

A Statewide Self-Determination Advisory Committee Report to the Department of Developmental Services

Prepared by

THE CALIFORNIA STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

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"The SDP has been a fantastic experience for my son, allowing us to tailor a program that fits his needs perfectly. With the support of staff who can accompany him to his activities, he has the opportunity to explore and engage in a variety of experiences."

-Town Hall Participant

Background

Since the statewide rollout of the Self-Determination Program (SDP) in July of 2021, enrollment in the program has continued to climb, allowing regional center consumers and families to exercise greater freedom and control in accessing the services and supports they need to live the lives of their choosing. The SDP is implemented by regional centers with the support of a network of Independent Facilitators, Financial Management Service Providers, and with the oversight of the Department of Developmental Services. As participation in the program expands, these stakeholders continue to work together to address emerging issues and systemic concerns, eliminating barriers and working toward making the program a success.

On December 4, 2024, the SSDAC held a Town Hall event, providing an open forum for members of the public to share their experiences with the SDP and offer recommendations to improve the program. The SSDAC asked members of the public to reflect on the five principles of Self-Determination: freedom, support, responsibility, authority, and confirmation, and what can be done to ensure that the program operates in alignment with those principles. The SSDAC is committed to fulfilling its statutory responsibility to monitor implementation concerns and systemic issues and believes that participants can provide key insights and offer unique solutions to the barriers that they face. By seeking this input and responding to the expressed needs and concerns of the community, DDS, regional centers and other stakeholders can implement policies and practices that lead to meaningful improvements in the lives of people with intellectual and developmental disabilities and their families.

"Self-Determination is a game changer and I love it. It is like having your very own day program but with the people that you know and trust. I recommend it."

-Town Hall Participant

Highlights

Freedom

Town Hall participants reported that they experience barriers to making choices about the supports and services they need because of limited options for paying for or being reimbursed for those supports. Lengthy processing times for spending plan changes and payment delays between fiscal years were also indicated as barriers, as they significantly delay access to services/supports that meet urgent/unmet needs.

Support

To support regional center consumers, Town Hall participants stated that we must ensure that they are all provided with the same information about the availability of, and the pros and cons of the Self-Determination Program. Additionally, regional centers can support consumers and families by providing greater access to linguistic supports (translated materials, bi-lingual service coordinators, etc.) and ensuring that those who provide support to SDP participants have greater disability and cultural awareness. Town Hall participants also expressed support for implementation of provisions in SB 1281 (Menjivar) and indicated a need for greater access to well trained, knowledgeable Independent Facilitators.

Responsibility

Self-Determination Program participants recognize that they have a responsibility to understand their own role in obtaining the services and supports that they need. Town Hall participants expressed a need for additional training, especially as it pertains to their responsibility as employers. The training and resources/materials that are provided to consumers and families must be in Plain Language to ensure greater understanding.

Authority

Town Hall participants expressed that they experience barriers to exercising authority over their budget/spending plan when regional center staff place unnecessary restrictions and/or fail to use a person-centered approach. Participants also expressed concerns about a lack of clarity and enforcement of Self-Determination Program directives.

Confirmation

SSDAC Town Hall participants expressed that they experience confirmation when they are able to work with a team that validates their goals and enjoys helping them make progress toward realizing success in the Self-Determination Program.

Public Recommendations

Freedom

- Make it clear to SDP participants and Financial Management Service providers what reimbursements are allowable and ensure that they are processed timely.
- Require that FMS providers allow access to advanced payment for goods and services that can't be paid via invoice.
- Require that FMS providers allow access to pre-paid debit cards for approved purchases.
- Explore options to allow spending plan changes through the FMS portal.
- Develop and implement a standard timeline for processing spending plan changes.
- Make sure clients and families are informed that they are not restricted to disability services providers and can choose services that will meet their needs.

Support

- Ensure that the SDP information that is provided to consumers, along with the formal acknowledgement that this information was received, is made uniform between regional centers.
- Provide additional training for families to help them better understand the SDP process.
- Collaborate with community-based organizations that can support families and selfadvocates on a cultural level.
- Ensure that Independent Facilitators are provided with robust training and fair wages.
- Create and/or promote resources to help SDP participants locate quality support services.
- Implement Provisions of Senate Bill 1281 (Menjivar), the Advancing Equity and Access in the Self-Determination Program Act.

Responsibility

- Increase access to Plain Language resources/materials regarding the consumer's responsibilities as employers.
- Provide additional training opportunities for consumers/families pertaining to their responsibilities as employers, regional center policies/processes, and how the SDP works.

Authority

- Provide comprehensive budget and spending plan training for regional center/SDP department staff.
- Standardize a spending plan template.
- Release a directive that addresses regional centers imposing POS standards on SDP spending plans.

- Provide deadlines for implementing directives.
- Provide direct oversight/monitoring of the implementation of directives.
- Consider how each directive will change regional center procedures and have very clear direction for all users.

Full Report of Public Input/Findings

Freedom

What barriers prevent individuals from making personal choices freely? How can we remove these barriers?

Freedom is the first principle of Self-Determination and is a primary driver of consumers interest in enrolling in the program. Self-Determination Program participants are seeking the freedom to decide where and how they want to live, how they will spend their time, and how they will receive supports and services. Participants in the SSDAC Town Hall identified the following barriers to accessing the freedom that the SDP is meant to help them achieve.

"Self-Determination has made a huge difference for my son. He has dual diagnosis autism and schizophrenia, and that prevents him from accessing traditional services. He now goes to a trainer three times a week and he takes Uber. He has some independence now that he is able to take Uber anywhere he needs to go."

-Town Hall Participant

Reimbursement and Payment Options

Town Hall participants overwhelmingly reported that restrictions on reimbursements and payment options impede their freedom in the Self-Determination Program. Though a good or service has been identified as necessary and approved by the regional center, limited means of making timely payments make them inaccessible for families.

"The ability to select specific goods and services is restricted when there is no option for family reimbursement. The FMS often takes a considerable amount of time to process these purchases, making it simpler for families to buy them outside of the SDP. This limitation hampers the choices available to SDP clients, taking away their freedom to obtain what they need."

"We need to make it clearer and more accessible when a participant does have the option to use a unique card to purchase some of their supplies. There are still many unmet needs."

"I want to ask why my FMS aren't allowed to reimburse payments anymore. There are situations where there are no gas stations that I've been provided cards for, or when my service dog needs to go to the vet. The vet does not want to go through the long, drawn-out process of getting vendorized. These issues are causing a lot of problems and taking away my freedom and choice."

"One of my concerns is if there is anything that would allow the parent or legal guardian to be reimbursed for [necessary] goods. The example I use is orthopedic shoes. Medicare doesn't cover it, but it's something that's required and that the regional center has approved, but you have to onboard the vendors even when you're only going to be accessing that service every six months."

"We are very rural, and IFs aren't able to be paid for travel time to [meet with] people they're supporting in rural areas. I would like to see a way for them to be reimbursed for their travel time and face-to-face meetings so that people have more access to their IFs when needed."

"I would love to see the opportunity for there to either be advanced pay or a debit card for specific purposes that would allow people to make purchases. My son was in the original pilot for 25 years and we had the opportunity for advanced pay to purchase stuff that you can't go to a vendor and bill for. People need money to access services and goods, or [they need] reimbursement."

PUBLIC RECOMMENDATIONS:

- Make it clear to SDP participants and Financial Management Service providers what reimbursements are allowable and ensure that they are processed timely.
- Require that FMS providers allow access to advanced payment for goods and services that can't be paid via invoice.
- Require that FMS providers allow access to pre-paid debit cards for approved purchases.

Payment Delays Between Fiscal Years

Town Hall participants expressed that they continue to face interruptions in services due to administrative delays when moving from one budget year to the next and requested that the Department work with Financial Management Service providers to address this issue.

"FMS agencies are not allowing clients to start their new year until they have the fully authorized POS. I have clients whose staff can't clock in. They can't pay any of their vendors. They can't do anything until the FMS has received the fully authorized POS authorization. That needs to be addressed."

"When my son's budget renewal happened, the FMS did not input it into their system. The first time that we realized this was when one of his one of his providers submitted an invoice. It was submitted in October and about three or four weeks later I got an email saying that that my son has no budget. I have a wonderful IF, and the team worked very hard. The FMS has apologized and reinstated the budget, but I want to know how there can be more transparency. This shouldn't have happened in the first place, but how can this be prevented?"

Spending Plan Changes

Town Hall participants reported that processing times for changes to spending plans create barriers to receiving services and exercising their freedom to address urgent and/or unmet needs.

"Regional centers [need to] be consistent with their timelines and response times to spending plan changes. There are regional centers that are taking over 60 days to process a spending plan change, even though we've given them all the information they need. This is causing a barrier [to making] last minute changes that are quite urgent and for unmet needs that come up."

"I have some solutions to offer. I have friends in Minnesota who are in self-directed services, and to move money on the spending plan, they just log into it on the computer. They may move a thousand dollars personal training to staff or vice versa. I can see needing a spending plan approved when it's a revision and you're adding completely new services, but when you just need to move money from [one area to another], it should not have to go through all the bureaucracy that we have right now. There should be a simple way to move those funds without going through all of that."

PUBLIC RECOMMENDATIONS:

- Explore options to allow spending plan changes through the FMS portal.
- Develop and implement a standard timeline for processing spending plan changes.

"Self-determination has changed my life for the better and helped me grow as an independent person. It gave me the courage to pursue my dreams of independent living and Culinary Arts. In my first year of being in the self-determination program I learned how to work my action plans to make progress toward my personal goals."

-Town Hall Participant

Other Considerations for Increased Freedom

Town Hall participants shared the following thoughts about barriers to exercising freedom in the SDP:

"Regional Center red tape, delays, and lack of response [restrict freedom]. [So does} the process being difficult to understand."

"FMS is a big problem in starting a new service or hiring new caregivers."

"Pre-determined "Program designs" by vendors are not adjustable to client needs because of contracts that we were not [involved in] creating."

"Undue influence by staff or facility, or relatives using Limited Conservatorships."

"You cannot decide for yourself. You always have to consult to be approved."

PUBLIC RECOMMENDATIONS:

 Make sure clients and families are informed that they are not restricted to disability services providers and can choose services that will meet their needs.

Support

What types of support do people need most to exercise self-determination? What existing supports should be improved or reimagined?

Although the Self-Determination Program offers greater freedom, choice and flexibility to participants, it is undeniably a more complex system to navigate than traditional regional center services. It is crucial that those who are interested in receiving services through the SDP are provided with sufficient support to understand the program (e.g., how it differs from traditional services, pros and cons, etc.) and to navigate the process of enrolling and accessing services.

Informing Regional Center Clients About SDP

Beginning January 1, 2025, regional centers will be required to have every RC consumer sign an acknowledgement that they have received information about the SDP. Town Hall participants expressed concern about ensuring that the information that consumers and families are receiving does not vary significantly between regional centers. They expressed that standardizing this information may be helpful in reducing racial disparities in SDP participation.

"[We must] ensure that every single consumer of every regional center knows about the Self-Determination Program. Right now, I would guess that the vast majority of consumers have never even heard of the program. How are you going to increase the numbers and make SDP the core of the system if nobody knows about it?"

"There is a lot of information [about the SDP] that is subject to interpretation, and some RC presentations might be more compelling than others [regarding] letting people know what the SDP is about. [That could] be avoided if we had uniform information in the form of a simple chart that shows pros and cons of the SDP versus the traditional model. If we had a standardized piece of information, much like the IPP is now being standardized, I think that's step in the right direction."

"Please streamline communication and build an easy-to-understand toolkit. SDP is different from one regional center to the next and from one family to the next. It's unfortunate that it seems that family A isn't treated the same or given the same opportunities as family B. There is a ton of misinformation out there."

"We are new to SDP but I am happy to interact in particular with our FMS provider's team as they have always been very responsive and help advise on ways to streamline the process for working with vendors."

-Town Hall Participant

PUBLIC RECOMMENDATIONS:

- Ensure that the SDP information that is provided to consumers, along with the formal acknowledgement that this information was received, is made uniform between regional centers.
- Provide additional training for families to help them better understand the SDP process.

Cultural/Disability Awareness and Language Barriers

SSDAC Town Hall participants overwhelmingly expressed the need for better communication at the regional center level and described a variety of concerns regarding cultural sensitivity, disability awareness, and the accessibility of services for people who speak a language other than English. Participants shared their experiences with feeling that their input is not being heard or valued. Self and family advocates alike

expressed a fear of retaliation from the regional center when expressing their concerns. Participants expressed a need for regional center staff and executives to listen to culturally diverse voices and center the voices of people who have lived experiences with disability, especially those with high support needs.

"I'm concerned about people who have cultural and linguistic barriers. Having a disability doesn't limit you to your race or your intersectionality. I want to suggest that the community think about people who have disabilities that are visible and invisible and how stigmatizing it is to have a multitude of disabilities that there's not much of a way to support. I can speak English, but there are some of us who don't have the means because their first language is not English."

"[People with disabilities need] to have an influential voice in making decisions affecting their lives. Not just a seat at the table, but to be acknowledged and truly seen - not invisible. "

"I want to speak to the fear of contradicting anything that comes from the regional center. My son is Latina. We're highly underrepresented [in SDP]. I have made a large attempt to participate in the regional center system to have my son's experience and voice be heard. Unfortunately, I haven't felt the embrace. I haven't felt cooperation or collaboration. I want to speak to the fear of retaliation, and what it looks like for my son. He's a non-speaker, so I really need to honor his experience."

"We definitely need [to listen to people with] more lived experiences. We need more representation of people like me that will speak on behalf of my son and that have his best interest [in mind]. My son is a 25-year-old man that is going to need significant support from the system throughout his life. We have experienced everything."

"[Self-advocate Self-Determination Advisory Committee members] are made to feel like their input is not valued by executive team members of the regional center, especially when they're raising systemic concerns and process issues. It speaks to a lack of cultural humility with respect to people with lived experiences. How do we make sure that that self-advocates who do open up and speak up about situations or bring problems to the SDAC are not being disrespected or made to feel like they don't amount to anything?"

PUBLIC RECOMMENDATIONS:

 Collaborate with community-based organizations that can support families and selfadvocates on a cultural level. "I want to say that thank you very much for the job you are doing. It's amazing. We started enrolling in this program and yes, there's some bumps and a lot of nuances, but it's an amazing program. Thank you very much."

-Town Hall Participant

Independent Facilitators

Town Hall participants expressed that SDP participants must have access to high quality, well trained, and ethical Independent Facilitators (IFs). They emphasized that these qualities depend on IFs being paid well for their services.

"Independent Facilitators that are part of our community and have expertise in different areas based on client needs. IFs are our lifeline. We need to make sure they are paid well so the industry is welcoming to those who want to make a career out of it."

"A few people have mentioned wanting a yelp-like resource and reviews. We are going through the SDP process for my 16-year-old daughter and spent the last two years developing a "yelp" for our community. We have a specific category for IF and FMS and we are a free resource so families and individuals can find, review and make lists of places to reach out to and favorites etc. www.theconnectedparent.net. We believe our directory and reviews allow more freedom and information when making choices."

PUBLIC RECOMMENDATIONS:

- Ensure that Independent Facilitators are provided with robust training and fair wages.
- Create and/or promote resources to help SDP participants locate quality support services.

Advancing Equity and Access

Senate Bill 1281 (Menjivar), the Advancing Equity and Access in the Self-Determination Program Act, was passed by the legislature in 2024 and would require that DDS establish statewide standardized processes and procedures for the Self-Determination Program, ensure that those processes and procedures are applied consistently by regional centers, and that they make measurable improvements towards achieving equitable enrollment by race, ethnicity, and regional center. Although this bill was vetoed by the Governor, it garnered widespread support from advocates and regional centers alike.

"The bill that the State Council, Disability Voices United, and others supported, Senate Bill 1281, was unanimously supported in the state legislature. The regional centers supported it, and yet Governor Newsom vetoed it. We are asking the Department of Developmental Services to implement the provisions of that bill."

PUBLIC RECOMMENDATIONS:

Implement provisions of Senate Bill 1281 (Menjivar)

Other Support Needs

Town Hall participants also identified the following as areas where additional support is needed:

"Supported living services should be improved beyond insisting upon background checks for personal care assistants."

"Accessing caregivers and transportation."

"More exposure to friends and advocates for those that are not able to easily speak or read."

"Support related to special Living Trust and CalABLE."

"Michael's life has transformed significantly due to access to SD. He has truly developed the story, budget and plan to support the way he wants live, and the needs required to support him in doing so. The process is an absolutely headache (and shouldn't be this way) but when you come out on the other end it's beautiful."

-Town Hall Participant

Responsibility

What responsibilities accompany self-determination, and what helps or hinders people in meeting these responsibilities?

The Self-Determination Program requires that the consumer/family take on a number of responsibilities that are not required of them under the traditional service model. SSDAC Town Hall participants expressed that they understand how important it is that they, as the consumer, are fully and adequately informed so that they can fulfill their responsibilities.

"It is still unclear what liability is taken on by clients and what insurance we need to cover ourselves and what it takes to be an employer. We have not done this before and no one is available to guide us on how to be employers in California, employment laws, etc."

"[There is a] lack of paperwork that is written in Plain language for clients to make their responsibilities as employers easier. [This is needed] if they have a difficult time reading and understanding various aspects of complex paperwork."

PUBLIC RECOMMENDATIONS:

- Increase access to Plain Language resources/materials regarding the consumer's responsibilities as employers.
- Provide additional training opportunities for consumers/families pertaining to their responsibilities as employers, regional center policies/processes, and how the SDP works.

Authority

What authority should individuals have over their own lives? Where do they face unnecessary limits?

The Self-Determination Program promises consumers that they will have the authority to control their budget so that they can purchase the services and supports of their choosing. Town Hall participants expressed that consumers/families that receive services through the SDP must be able to exercise their authority over their budget and have responsive and trustworthy support in place for when help is needed.

Individual Budget/Spending Plan Development and Approval

Town Hall participants expressed that unnecessary limits are being placed on consumers as their budgets and spending plans are developed. These limits sometimes come from Financial Management Service providers placing restrictions, but the most prevalent concern that was expressed was about regional centers lacking an understanding of how to use a person-centered approach to developing budgets and approving spending plans.

"We are using still traditional models in the budget development phase. Although there is a person-centered plan in place, there are not person-centric approaches being used to develop the budget."

"There has to be additional training [for regional centers]. I want to see a directive that talks about the regional centers trying to impose the POS standards on the spending plans. While they can use those standards to create the budget, they

are also trying to use those standards on service codes that are not in the traditional system."

"I echo everybody else's thoughts [about regional centers using] the traditional model as a baseline which even today, after so many years of SDP being in place, the case coordinators are not very familiar with how to actually bring uniqueness to the SDP for their clients."

"Regional Center of Orange County micromanages the spending plans to the most ridiculous point. It completely removes the freedom aspect of self-determination and I've asked the ombudsperson office to address this in the past. Then we have GT independence who's micromanaging differently, so it's almost impossible to get a spending plan that Regional Center of Orange County and GT Independence both agree on."

"The regional centers are working on a uniform IPP template. Let's do the same for the spending plan. I think this helps streamline and prevent barriers because it prevents delays in getting changes implemented. There are some amazing ones that some regional centers are using and there's some very non-practical ones that many regional centers are insisting on using. Oftentimes there's two templates being used concurrently because the FMS has to have theirs, and the regional center has to have theirs, causing more delays. It would be great if we could also see a uniform template."

"FMS policies are restricting; participants cannot freely choose providers. Some RCs do not seem to know the SDP law."

"The individual budget is where they sometimes have unnecessary limits. Service budgets are not always prepared for individuals unexpected expenses."

PUBLIC RECOMMENDATIONS:

- Provide comprehensive budget and spending plan training for regional center/SDP department staff.
- Standardize a spending plan template.
- Release a directive that addresses regional centers imposing POS standards on SDP spending plans.

Enforcement/Clarity of Program Directives

The Department of Developmental Services continues to respond to identified issues within the Self-Determination Program by releasing timely directives. SSDAC Town Hall participants recognized the Department's efforts to improve the program but expressed concerns about their enforcement. Participants emphasized the need to ensure that program directives are clearly communicated to all affected parties, include a timeline for implementation, and are enforced in a uniform manner.

"I want to talk about the directive released on December 26, 2023, that stated that the FMS needs to pay for local businesses in the manner that they are typically bill. Many of the FMSs are not doing that. I want to make sure that since this directive already exists that DDS is going to enforce that directive." "Regional Centers that do not clearly understand SDP rules and hide behind "we need to ask DDS."

"The regional center seems to find directives more aspirational than mandatory. I'm wondering what plan there is to make it uniform with regard to a timeframe in which [regional centers] must adopt them, because we're getting pushback. I'll send a directive to my son's service provider and say 'we'd like you to do X according to this directive,' and they have this sort of nonchalant attitude about it. [They say] 'well, we'll get to that' or 'I haven't seen that before, I'll consider it.' I'm wondering if there's any way to make it a little bit teethier so that things can be uniform."

PUBLIC RECOMMENDATIONS:

- Provide deadlines for implementing directives.
- Provide direct oversight/monitoring of the implementation of directives.
- Consider how each directive will change regional center procedures and have very clear direction for all users.

"I am a parent of a 26-year-old Regional Center client and a former IF. Living in a rural county, SDP has been a lifesaver for my son. He did not have a day program for months due to staff shortages. With SDP, we were able to hire an amazing Direct Support Professional, who also serves two other individuals. My son has never been busier and is happy to head out each day."

-Town Hall Participant

Confirmation

How can we ensure individuals feel acknowledged in their selfdetermination? What recognition and validation are most meaningful?

SSDAC Town Hall participants offered the following thoughts about how Self-Determination Program participants can be affirmed and recognized as the primary decision makers in their own lives:

"Having a team that is encouraging and happy to be working together and celebrating incremental improvements, not a team that seems to be looking for ways to limit what can be done in SDP. This includes the FMS, RC, IF, and Circle of Support."

"Having needed support, being supported by people who enjoy working with the participant. Making progress on their goals, feeling good about themselves and about being allowed to make their own choices, and being supported by personcentered thinking staff."

"Validation of their dreams and goals."

"By recognizing the efforts they put into Self-Determination. They should be recognized for that constantly."

"We can support individuals in feeling acknowledged in their self-determination by recognizing and authorizing their requests or wishes. If those wishes are not in line with regulations, we should offer guidance on how they can proceed to help them achieve their goals."

"Making sure that people are safe and healthy and satisfied with their lives and doing what they want to do is essential to the success of the Self Determination Program."

"My son is a 25-year-old young man that has high needs and I wanted to speak very favorable on the self-determination program that has really been a life changer for my son. He requires two-on-one supports. before the self-determination program, he really didn't have the choice to receive that support at home. So that's been a huge life improvement for him, choice and freedom."

-Town Hall Participant