



State Council on Developmental Disabilities



STATE OF CALIFORNIA
Gavin Newsom, Governor

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April 3, 2026

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

RE SSDAC TOWN HALL; SUPPORT FOR CONTINUED FUNDING

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 assistance and coordination in the planning of the SSDAC Town Hall event on February 17th, 2026. The SSDAC appreciates the opportunity to assist the Department in collecting input from the public as the Department works to renew the Self-Determination Program Waiver. SCDD and SSDAC thanks the Department for being present that day. SCDD has gathered the information and stories shared during the event and is pleased to present the enclosed report to the Department.

The enclosed report reflects Town Hall participants' and SSDAC members' experiences with the SDP and demonstrates the positive impacts that the program has on its participants. In sharing their stories, SDP participants, their family members, and people who serve them consistently expressed that receiving services through the SDP has increased participants' inclusion in their communities, allowed them to obtain and maintain meaningful employment opportunities, and provided them with flexibility to hire and retain qualified, safe, reliable and culturally appropriate service providers. Many individuals expressed that the SDP has transformed their lives, providing them with the support to better manage their physical, mental, emotional and behavioral health and supporting them to live more independent lives.

The SSDAC submits this report to demonstrate to the Department and to the Centers for Medicare and Medicaid Services (CMS) that the individuals and families that participate in the Self-Determination Program consistently report transformative outcomes and positive impacts on their quality of life. Program participants, their family members, and their service providers alike attended this event to express their adamant support for the continued federal match funding of the program.

"The Council advocates, promotes & implements policies and practices that achieve self-determination, independence, productivity & inclusion in all aspects of community life for Californians with developmental disabilities and their families."

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

Kindest Regards,

A handwritten signature in blue ink, appearing to be 'Aaron Carruthers', with a stylized, looped design.

Aaron Carruthers, Executive Director
State Council on Developmental Disabilities

A handwritten signature in blue ink, appearing to be 'Rick Wood', with a cursive style.

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

A handwritten signature in blue ink, appearing to be 'Nestor Nieves', with a cursive style.

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

Making an Impact

Insights from the February 17, 2026,
Town Hall and the Importance of
Continued Funding



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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“It’s important for SDP funding to continue because the program allows [my son] to do the things he loves, keep the staff that he has gotten to know, and to live independently.”

Background

The Statewide Self-Determination Advisory Committee (SSDAC) held a Town Hall meeting on February 17, 2026 to gather feedback from the community about the outcomes and impacts of the Self-Determination Program (SDP), and to hear about why the continued federal funding of the program is important to program participants, their families, and to the professionals that serve them. This report of their comments has been compiled for submission to the Department of Developmental Services (DDS) as part of the Public Comment period for the renewal of the SDP Waiver Application. The SSDAC believes that it is critical that DDS and the Centers for Medicare and Medicaid Services (CMS) are aware of the benefits that the SDP provides for participants and their families and are informed about the community’s enthusiastic support for the continued funding of the program.

As DDS and CMS work toward the approval of the SDP waiver, the SSDAC would like to express its unwavering support of the program. The Committee wishes to emphasize that the SDP is exceptional in that no one who is participating in the program is not utilizing services. The Committee also notes that once individuals have enrolled in the program, the regional centers see very few of them drop out - suggesting that for those who are seeking an alternative to traditional regional center services, the SDP is providing a successful model. The Committee stands in partnership with the intellectual/developmental disabilities community and with the Department in commitment to continuing and furthering the success and sustainability of the Self-Determination Program.

“Continued federal funding for SDP is essential. This program allows our son to live safely at home, with dignity, and with the support of his family.”

Full Report of Public Input

What Makes SDP Different

The SDP is different from the traditional regional center service delivery system in a variety of ways. For many families, those differences translate to a complete transformation in the way that they and their loved ones are living their lives.

Participants and family members shared their experiences with both models, explaining why the traditional model did not adequately meet their needs and how the SDP solves long-standing problems in California's service delivery system.

“When you have a child with autism, some changes are incremental and some are huge. SDP falls in the second category. The school system served her fairly well, but afterward there was nothing. The traditional regional center model offered little that fit her needs. SDP has allowed us to find workers who meet her schedule needs and don't end at 5 p.m. Monday through Friday. Before SDP, she worked with an employment agency and traditional vendors, but they weren't flexible and didn't have the bandwidth to get to know her so they could help her find a job that's a good fit. She grew despondent about not having job support and being home as a 25-year-old. The biggest change has been access to community-based activities that help her feel that life isn't passing her by, which is what she felt like when she was stuck at home with her parents. SDP has changed her view of what she can achieve. She lives in an intentional community in her own apartment and says it's like a gem, something that's precious and hard to find. Her life is rich now, where she was isolated before. Now she's able to reimagine what she wants her life to be because she has the help she needs, and that's really what SDP has done for her.”

“I'm here as a parent of two dynamic young men, one is 19 [years old] and has been in Self-Determination going on a sixth year and the second is 16 [years old] going into his second year. What we're seeing is reflective of a system that is centered on the people it serves - person-centered. It has taken our traditional system over 55 years to try to get it right, and I'm not going to throw them under the bus because we depend on the traditional system - But [we can all see] in the POS reports that every regional center submits [that there are] issues, challenges, barriers, and disparities - whereas Self-Determination can address that. The system hasn't evolved the way it should have, and Self-Determination helps bring that into a course-correct and balance.”

“The Self Determination Program has immensely and positively impacted the life of my daughter. I also believe that the SDP program saves the State of California money and encourages prudent and effective financial choices because the SDP decreases unnecessary paperwork and delay in the "traditional" process, and also because the SDP participant is given more flexibility and authority to use what is most effective and desirable to them- thus increasing the efficacy of the entire program for both the individual and the funding source. Before SDP, my child often could not enroll in swim classes or physical fitness classes because the providers were not "vendorized" with the regional center, nor did they have any interest in being vendorized because it was additional work - especially for small, local businesses. However, SDP opened up a whole new category of potential classes and activities that my child can participate in without going through the normal vendorization process of the regional center. My child's confidence has substantially increased as she proudly tells me about her progress in swim class that *she* chose and that was available to her at a convenient time. Same for a physical fitness class that she loves and helps keep her healthy and that is also close enough to home that she can attend. Likewise, engagement in these classes has increased the financial stability of several local businesses. Our family enthusiastically endorses the SDP and urges its continued adoption and operation.”

“I am the mother of an adult son who is currently transitioning into the Self-Determination Program. My son has many goals, plans, and dreams that he wants to accomplish. Unfortunately, under the traditional service model, he has experienced delays in accessing quality services, which has limited his ability to fully pursue those goals. We are grateful that the Self-Determination Program exists because it offers flexibility, person-centered planning, and opportunities for independence.”

“[I have adult son] with autism and an intellectual disability. Traditional services made his life worse. Day program and respite put him in places not of his choice, with people not of his choice, doing things not of his choice. Self-Determination literally saved his life. Either he or I, or both of us would not be here today without SDP. In SDP, he spends time with people of his choice, doing things that interest him. He contributes to the community, and they appreciate him. Everyone who knows him says he has grown tremendously through his time in SDP. He is a voice over actor, participates in theater classes, and has written a children's book with his own created characters who tackle a problem and how to solve it. He is currently, with the help of his aide, reaching out to schools and libraries offering to come in and read his book as a self-advocate role model of how anyone can do anything with the right support. SDP is the right support.”

“For our family, SDP has been transformative. Before enrolling in Self-Determination, my son qualified for more services than he actually received. Due to provider shortages and system limitations, those supports simply were not available. On paper, he was eligible. In reality, he was underserved. He worked four hours twice a week with job support and received about four hours per week of independent living services. The rest of his time was largely unstructured, and he spent most days at home playing video games. He was isolated and not reaching his potential not because he lacked ability, but because the traditional system could not meet his needs.”

“I run a DJ company here in Santa Barbara. Self-determination really helped me expand my reach and allowed me to do things that I haven’t been able to do before.”

Community Inclusion

People with intellectual/developmental disabilities often struggle with isolation, whether that is due to needing complex supports that are traditionally provided through an institutional setting, or due to the barriers that they face in participating in activities and events that are taking place in their own communities. SDP participants and their family members describe how participation in the SDP has led to them experiencing much greater levels of inclusion in their communities by providing supports that allow people to stay at home with their families as opposed to in an institutional setting and by providing access to opportunities for people with disabilities to engage in activities outside of the home, building relationships that bring connection and meaning to their lives.

“My son who has autism as well as learning issues was approved for SDP last year, and like so many others, the SDP has made an enormous positive difference in his life. His overall health and wellness are significantly better. He's no longer lonely and stuck in a room at home on his computer for most of the day, but his personality has been transformed into a joyous, extremely social presence. He now has an individualized fitness program, proper nutrition, and a wide range of friends. The extensive community engagement provided through his SDP has made him so much happier.”

“My son is a young man with intellectual disability, autism, and complex neurological and medical needs. He requires constant supervision and specialized behavioral and medical supports to remain safe in his home and community. Without the Self-Determination Program, [my son] would likely require placement in a congregate institutional setting. SDP has made it possible for him to remain at home, surrounded by the people who know him, respect him, and can respond safely to his needs. SDP has preserved his dignity. He is not defined by his disability. He is a person who deserves stability, respect, and the opportunity to live in his home and community. SDP makes this possible by allowing services to be individualized and responsive, rather than forcing him into systems designed for administrative convenience rather than human need.”

“In the traditional system, [my son’s] only real option would have been placement outside our home, away from his brothers and family. This would have separated him from the people who know him best and who are central to his safety, well-being, and quality of life. The Self-Determination Program has been life-altering for our family. Because of SDP, our son is able to live at home with his brothers and family, where he is safest and where he belongs. Our family is able to care for him, advocate for him, and make sure he receives the right support.”

“My adult daughter is medically complex and has high support needs. While she was in school through age 22, she had built-in structure and opportunities for engagement, but since she aged out of school our family faced a hard reality: there were no traditional adult day programs that truly worked for her. The available options were not a fit for her communication style, sensory needs, and the level of individualized support she requires. Without the right support, she was at real risk of becoming isolated at home, not because she didn’t want a life in the community, but because the system couldn’t adapt to her. Because of the Self-Determination Program, we have been able to create a customized program that actually gets her out into the community in meaningful ways. It is working and it’s visible in her happiness and engagement.”

“A huge benefit of the SDP is [my son’s] ability to access activities in the community, learn new skills, [develop] friendships and be out and about in the community. [My son] has been able to not only attend events/activities but also get personalized support at those activities which has allowed him to have more interaction with others, make friends, and engage in the community. He has been able to go to the movies, attend musicals, do sports, visit the library, learn ceramics, do community gardening, and much more all due to the personalized support he receives through SDP. He can choose activities he wants to do, and even be involved in planning them, as a result of the SDP. “

“Our son has been a participant of the Self Determination Program for 6 years now. With SDP, he's able to hire consistent staff support and build long-term relationships. He has also recently transitioned out of his Augmentative and Alternative Communication device thanks to his coaching services and supports. Our son's quality of life has greatly improved via SDP. He's able to meet new friends and have a great community of support.”

“The availability of transportation funds [in the SDP] has been really important in helping [my child] get to work, appointments and school, but also in keeping him active in his community where he participates in musical theater and church.”

“Since enrolling in SDP, [our son's] life has changed dramatically. He now participates in supported social events, meets weekly with a dietitian, takes cooking and enrichment classes, builds meaningful independent living skills, added an additional internship, and participates in a peer walking club. His days are structured, active, and purposeful. Most importantly, he is happier. We see it in his confidence and growing independence. He is no longer simply filling time. He is building a life. We could not afford these services privately. Without SDP, these opportunities would not exist for him. The program did not create new needs it made it possible to meet the needs he already had. The Self-Determination Program has turned isolation into engagement and limited services into meaningful growth. This program gave my son a life, not just services.”

“The [Self-Determination] Program allows [my daughter] to take part in community-based activities by covering the cost of support staff and transportation. This assistance is fundamental to her quality of life. It gives her the opportunity to build friendships, develop social confidence, and remain actively connected to her community rather than isolated from it.”

“Without SDP [my son] would not be able to live [in community housing] or participate in [his vocational training program], and he would have to be bussed out of our community every day. It is very unlikely that he would be able to find a suitable shared housing or Board and Care facility, since they are scarce and in much high demand. SDP has been critical in helping [my son] achieve the most independent and functioning possible for him.”

“Through SDP, we were able to get a personal assistant with independent living support for about 15 hours a week with an enthusiastic college student who had a personality that met [our daughter's] needs. He helped her with physical activity, meal preparation, public transportation, and accessing the community. She applied for a program and is living independently because she was able to get out of the house and learn skills. She's living in a program with other autistic

roommates and gets full support. She has opportunities for community, creative expression, for work, and building self-confidence. Without SDP there's no way she would have been able to be in a program like this. It has fully transformed her life."

"Since my son began participating in the program, we have seen very positive changes. He has had opportunities to go out into the community, spend time with other people, and develop skills that strengthen his independence."

Maintaining Meaningful Employment

Participants and their family members consistently state that the SDP has allowed them/their loved ones to pursue meaningful employment in the fields of their own choosing. For some of these participants, SDP has unlocked access to technology that was unavailable to them before. For others, the ability to hire employment support staff outside of the traditional system has given them the flexibility to work in fields that do not support standard work schedules has opened up new opportunities. Many SDP participants have reported that the supports the program has made available to them have led to them developing successful micro enterprises, bringing forth a cohort of entrepreneurs who otherwise may not have had the resources to develop their talents and business management skills.

"Prior to the SDP, [my son] had one agency for employment supports and second for supported living. The staff turnover for both agencies was astounding, and not knowing who was going to show up as his staff each day made him very anxious. He had four jobs prior to entering the self-determination program. After entering SDP, he was hired for his dream job at a golf course. He has had the same support staff person and will celebrate five years at his job this year. His employer loves his support staff as much as they love Shawn. He also designs T-shirts, is a keynote speaker, and his staff support him in selling his shirts at events and [with] social media. His staff have traveled with him to speaking engagements across the country."

"What I would like to share is that with SDP, I was able to get technology that helped me be able to complete my degree in social work, which allowed me to get a job within the service system that allows me to help make it better. Without Self-Determination I probably wouldn't have been able to do that. I fully

financially support myself without the assistance of Social Security benefits, which was a personal goal of mine.”

“Once [my daughter] entered SDP she was able to engage in her own micro enterprise. She loved dogs and she had a dog treat business. She also volunteered at Priceless Pets. She worked at Dickie's Barbecue because the owner asked if she was interested in working there. They loved her personality. She had Down syndrome and a lot of medical issues, but she continued going all the time. [She would say] ‘mom, they have to have me there. Mom, I have to be there. They're going to miss me.’”

[My son] has been successful in maintaining part-time employment as a warehouse clerk, as the SDP program enables him to get specific employment support around issues of being independent, communication and following directions at his job. This enables him to interact with the working world, and gain experience and more independence.”

“SDP funds are vital to my daughter’s independence, health, and meaningful participation in her community. They make it possible for her to hire qualified staff who can support her at her preferred workplace, including during non-traditional hours outside the standard Monday-Friday schedule. This flexibility is essential, as it ensures she receives the assistance she needs until both she and her employer are fully confident in her ability to perform her job independently and successfully.”

“For my son, perhaps the most significant difference between the SDP model and a traditional service model is in the area of employment support. He has many challenges, but one of his strengths is the ability to work with a very specialized technology, geographic information science. There's no way for traditional services model to support him as he pursues employment in this area, since his job support will require knowledge of this specialized software and he will need to be able to hire the right person to help him succeed with an employer. The SDP is making it possible for [my son] to get the proper individualized support so that he can not only achieve independent living, but productive employment.”

“SDP has allowed our son to live a meaningful fulfilling independent life. Without the support of SDP he would be stuck living at home with aging parents and no appropriate outlets to engage with peers, community and work.”

Provider Choice

Participants and families state that through the SDP, they have the freedom to hire who they want to provide services, and to pay their staff competitive wages. This freedom translates into better relationships with caregivers, more flexibility in their schedules, the ability to retain staff long term, and the ability to access providers from within their own culture and community. These participants and families emphasize the importance of building strong relationships with those who support them, and how the continuity of care leads to better long-term outcomes and peace of mind.

“With Self-Determination you have the flexibility to think outside the box in terms of who [you can] get to provide a service and how that needs to happen. If you're just with traditional services, that can't necessarily be done. For those like me - Black, African American, and those who are minorities from the underserved communities, many are not getting any services at all. We know that this is a reality, but SDP has helped to bridge that gap. You have the opportunity to pick culturally sensitive providers. You have more choice and you have more freedom.”

“Being able to hire my own staff and choosing who I want to work with has been the best thing about Self-Determination. I have been able to hire people who live close by and share my interests, and they're able to assist me with cooking, cleaning my house, and running errands.”

“[In SDP I'm] able to hire the supports I need. One of the things that made me want to go into [working to make] the service system better was how direct support people would treat me. They treated me not fantastically, just based on the way I walk, or the way my speech is. I didn't like that. Getting to hire people that aren't going to treat me that way is great.”

“The most important impact of SDP has been stability. [My son] depends on caregivers who know his communication style, his triggers, and how to support him safely when he experiences neurological episodes that can cause stiffness and loss of voluntary control. Under traditional services, frequent provider turnover and rigid service models created instability and risk. SDP allows us to maintain consistent, trained caregivers and clinical professionals who understand him as a whole person.”

“SDP allows us to choose and train caregivers who understand [our son's] needs. We are able to ensure caregivers are properly trained and that his support is consistent and safe. This stability protects his health and prevents crisis situations. We are proud of this program and strongly support it. It allows our son

to live with his family instead of being separated from us. It allows us to manage the quality of his care and ensure he receives the right support.”

“Before entering the Self-Determination Program (SDP), my children had very limited access to providers. It was extremely difficult to find qualified support, especially for my Deaf-disabled daughter, whose communication and language needs are unique. Agencies were often unable to send providers with the appropriate skills or training. Through SDP, my daughter can now hire her own providers and build a schedule that truly reflects her needs, interests, safety requirements, and communication needs. This allows us to create a program that supports her independence today and prepares her for a future when we, her parents, are no longer able to provide support.”

“SDP funding allows [my daughter] to offer competitive wages to the staff members who provide her support. This is crucial for recruiting and retaining skilled, dependable professionals who understand her needs and can provide consistent, high-quality care. Continuity of support is not simply beneficial, it is essential to her stability, progress, and safety.”

“Self-Determination has been life-changing for my son and his staff. It gives me peace of mind knowing he is cared for by people who truly care about him. Continued funding is critical to his success and my peace of mind.”

Health and Wellness

People with disabilities often have unique health-related concerns and/or co-occurring medical diagnoses, in addition to any physical differences that may make exercise or other self-care activities more complicated. SDP Participants and their families describe how accessing supports like physical training, wellness training, meal preparation and planning, etc., in addition to accessing specialized caregivers and clinicians play a vital role in enabling program participants to live healthy lives.

“I am the parent of a 27-year-old daughter who has received SDP services for the past three years, and they are so beneficial because we truly have a customized program that aligns with the person-centered approach that the regional centers have said is [the approach they desire]. Because of SDP, we are able to have a wellness program that includes a nutritionist, so [my daughter] not only gets healthy meals, but she understands what a healthy meal is, and it helps her to create the right kind of shopping list to align with a healthy diet. In addition, she has a wellness trainer so that she starts understanding and experiencing why exercise is so important in keeping both her weight levels well and an increased confidence in her abilities.”

“I'm the parent of a 25-year-old daughter who has a rare genetic condition that makes various things difficult for her. She has medical issues, but she also needs 24/7 support for social interaction and safety in general. She has been part of the SDP for about three years, and it has made a huge difference for her. She [used to be] very isolated at home with me and wasn't enjoying the traditional regional center model. She didn't feel comfortable there. She wasn't doing things she enjoyed. With SDP we've been able to focus on what makes her excited about life. It has also helped her with her physical difficulties by giving her the individual attention she needs so that she can make incremental progress. It's not so much nursing or medical care but being able to hire staff and have staff members who know her and [who] can advise her. We've seen a big improvement in her health. She requires fewer medical resources than she used to, and she is also able to participate in the community so much more.”

“SDP allows [us to] access specialized clinical expertise that would otherwise be unavailable. [My son] requires guidance from highly specialized clinicians who train his caregivers and family to support him safely. This clinical continuity prevents injury, avoids crisis situations, and protects his physical and emotional well-being. The ability to select qualified providers based on clinical need, rather than vendor status alone, is essential to his safety and quality of life.”

[My son] has gained independent living skills through SDP support of his daily needs, such as hygiene, cleaning chores, physical exercise, meal planning and preparation, and grocery shopping. Through SDP, he works regularly with a registered dietitian and has a coach/trainer for his exercise programs which have resulted in him learning and understanding more about healthy eating habits, sleep and fitness. Based on these healthy choices, his weight has come down, and his physical health has improved and is a point of pride for him. Further, the SDP program enables him to receive support around health and wellness, when it is needed, beyond the traditional model of Monday through Friday.”

“SDP funding enables [my daughter] to work with a registered dietitian who provides critical guidance with meal planning, grocery shopping, and meal preparation. These services are not optional; they are medically necessary. Because she has high cholesterol, professional nutritional support plays a key role in protecting her long-term health and preventing serious complications. In addition, SDP resources allow her to participate in individualized fitness training that further strengthens her physical health, stamina, and overall well-being.”

“SDP is not an expense; it is an investment. It is an investment in inclusion, independence, and long-term outcomes. Programs like SDP must continue so children and adults like mine can be included in their communities, participate meaningfully, and be respected as individuals.”

Mental/Behavioral Health

People with disabilities often struggle with co-occurring mental/behavioral health conditions or disorders. These unique challenges often lead to isolation for these individuals and their families as they struggle with emotional and behavioral regulation. Families and participants describe how accessing the right mental/behavioral health supports through the SDP have transformed their lives and the lives of their entire families.

“I am the mother of [a son in] his third year in the Self-Determination Program. This program has greatly changed my son’s life. His behaviors have improved significantly. He used to have behavioral challenges, and the program has helped him a lot. He now has a home-based program designed around his goals and specific needs - academically, in language development, and in independent living skills such as cooking, cleaning his room, doing his laundry, and vacuuming. It also includes recreational activities that help him integrate into the community through things that make him happy, like dancing, piano, swimming, karate, and sports. He needs a personal assistant because he has difficulties with attention, focus, and safety awareness; he does not recognize dangers, and having a personal assistant helps redirect him and teach him how to behave appropriately.”

"I speak as a parent of a neurodivergent young adult with autism and several co-occurring mental health conditions and PDA. Prior to Self-Determination we had no services from the regional center. The only thing we had was respite, which did not serve our purposes. Then the pandemic happened and that's when we learned about the SDP. It came at a time when we were in a state of complete crisis. There were nights I had to spend in the car while my child was going through a hormonal issue and other dysregulation regarding behaviors. Nothing seemed to help. She stayed home for almost 13 months, and she didn't want to get out of bed due to depression. The Self-Determination Program gave us the opportunity to get more person-centered supports and to hire and train people to work with her. Our Independent Facilitator and person-centered planner actually made us realize that [our daughter] needed to be heard and understood. My child is minimally verbal and is not able to communicate the way many of us do. That was the turning point in our relationship with her and in her life. Today, she attends a post-secondary program, accesses the community, and goes to events and social groups with her support team. She does have issues with regulation but typical ABA and behavioral programs did not work. We need to have very person-centered supports with people who understand her. Self-determination made that happen for us. She's able to live life thanks to the SDP."

"Before Self-Determination I was the person who was shut down and I took a bunch of pills. I was hospitalized and I almost didn't make it. But now with Self-Determination, I was able to get support. I lost the weight I had gained, and now I'm under 300 pounds because of the help of Self-Determination. I was able to get computers and I'm set to start my own business as part of my person-centered plan and my IPP. It really helps. Self-determination changed my life."

"[My daughter] is in her second year of SDP. She has autism, anxiety, ADHD, OCD, and depressive disorder. She's 27 and had been out of high school for seven years and had almost no services at all. She was depressed and would not leave the house. The services offered to her through the traditional program didn't apply to her and she couldn't voice to us what she would need with her autism and mental health conditions. Within one year [of joining SDP], her entire life was transformed. Her independent facilitator created a person-centered plan after spending hours getting to know her and finding out what she really wants. She wants to have creative expression, she wants to get out into her community, she wants to work, and she wants to be able to live independently. [After joining the SDP], she's living in a program for autistic individuals where she's able to do creative expression and lives with other autistic roommates and gets full support. She has opportunity for community, creative expression, for work, and building

self-confidence. Without SDP there's no way she would have been able to be in a program like this."

"My son has been in the [SDP] since the beginning, and it has been a great experience. It has allowed him to live his dream. He's in a community theater production and he's done seven or eight of those because he has had that choice. He was very depressed in the day program. He did not want to go, and there wasn't another option. [SDP] has given him the ability to have a life that he is very happy with."

Independent Living

For some SDP participants, the program has been instrumental in allowing them to live independently.

"Before the SDP, I lived in group homes and attended day programs. I was depressed and wheelchair-bound not because my legs didn't work, but because of other people's liability. I am no longer wheelchair-bound. I am functioning. I am not surviving; I am living. I am working. I am making my life what I want it to be. I really would like to continue living my life. I own my own home. I have a service dog that assists me. I have 24-hour care combined from IHSS and the people I hire myself. I live the way I want to live in a world that doesn't make life easy when you have a disability. For me, this program is vital."

"The Self-Determination Program has helped me tremendously. The traditional model wasn't very helpful. I'm very happy with Self-Determination. I get to be with the agency of adult support, and I get to live in my own house, in my own community. Self-Determination helped me to live in my own apartment. It helped me to translate for Mandarin families. It helped me do social recreation. Being autistic and having mental health issues is not easy. When I don't have the right support, I go to 5150, and I get restrained, and I don't feel like group homes and crisis centers are helpful for me."

"Continued federal funding is critical. Without SDP, [my son's] stability, safety, and ability to live at home would be at risk. SDP is not an extra benefit, it is a lifeline. It allows individuals with significant disabilities to live with dignity, safety, and meaningful support in their communities."

Why Continued Funding for SDP Matters

SDP participants and their families were eager to share why they overwhelmingly support and advocate for the continued federal funding of the program.

“I have personally seen over 200 lives changed. [SDP is] life-changing, not just for my daughter, but for other SDP participants. They have qualified assistance/staff for the first time in their lives. This is how it has been for me, and also for the clients and families that I know. Quality of life is what I often hear. I volunteer for many hours for the Local Volunteer Advisory Committee and also as a speaker regarding the SDP. If it was not such a valuable and necessary program, I would not have continued after my daughter passed away.”

“We have a 32-year-old son with Down Syndrome. This is our third year in the Self-Determination Program. It has opened doors for him, allowing him to have a full life with purpose. He can design a program that meets his needs and goals, bringing him joy and a sense of accomplishment. He’s 32 years old—he wants independence. SDP gives him that opportunity in ways a traditional model would not. The program has given our son a voice. He knows he matters. What he wants is heard and respected. We are grateful. It has been life-changing for our family.”

“My 19-year-old autistic son is in his first year in the Self-Determination Program. This program has been incredibly helpful in exposing him to real life. Thanks to this program he is [attending] college with his personal assistant, and he can attend his swimming and music class and learn how to behave in public. Thanks to the SDP, my son is more engaged in preparing for a better future, and his stress has decreased significantly. Please ensure this program continues to support our kids.”

“My identical twins are 26 years old, and in addition to intellectual disabilities they have a seizure disorder that is not totally controlled. Without the SDP, they would not be able to participate in all kinds of activities, from social engagement to fitness programs, but more importantly to things like volunteering and job activities. Their programs allow them to have support during those activities, so that when they do have a seizure, they have somebody to help them with the moments of confusion. Without these programs, they would be sitting at home, not able to interact with the community. As parents, we want our children not to be dependent upon us, but to be able to live lives like other adults with a fulfillment and social relationships and the happiness, ultimately, that it brings them.”

“We have a daughter who has cerebral palsy, and this is our second year in the SDP. SDP is a great program and it really helped my daughter to increase her cognitive skills. Before we got into the program, we really had issues with her services. Now we can choose the right services for our daughter. The program is wonderful. Not only for us, but for all the people that have disabilities.”

“Continued federal funding for SDP is essential because families like ours need the flexibility to build supports that fit real people, especially individuals with higher support needs who often don’t fit into standard programs. SDP prevents isolation, reduces crises, supports health and stability, and makes true community inclusion possible. Please protect and strengthen SDP so it remains available statewide.”

“The SDP has been enormously positive and beneficial to [our son]. [His] quality of life has improved and his competencies have increased. With SDP, [our son] has a voice in determining who he works with, and through the SDP these professionals can be paid a competitive salary. We have been able to find professionals to work with and understand [our son’s] specific needs and meet those needs, who have built a relationship of trust and are highly effective. These professional relationships have resulted in huge stability in his life and in supporting his needs. We have seen increased confidence and maturity in him as a result of the support that he is receiving through SDP.”

“The improvement to our son’s access to services, and to the rate at which he is cultivating increased independence, socialization and community integration, has been transformative. We can now see a plausible path toward sustainable employment and a more resilient lifestyle, as he becomes more confident in approaching the future.”

“Continued funding for SDP matters to me because I survived in traditional services, but I live in the SDP. I love my life now. I am an integrated and functional member of my community. I walked away from the wheelchair I was forced to use in traditional services because other people had “liability” if I have a seizure and fall down. I now have dignity of risk. I provide jobs to people in my community. I have 24-hour care in my own home, which I own and pay a mortgage on. I am working, paying taxes and living a joyful life. All of this is dependent upon the SDP funding. I only get 14 hours of IHSS per week, but I need 24-hour care. The rest of my services come from the SDP. I have a representative payee who helps me pay my bills and benefits counseling so I can work. I have an art program so my life is enriched. I have a service dog who helps me be more independent. I hire my own staff and pay their mileage so I can go out in the community. My life is actually worth living now.”

“The progress my son has made in the last 2 1/2 years in SDP has been mind-blowing. He literally went from doing nothing almost to being out every day, expanding his horizons learning life lessons. I don’t even have the words to be able to [say thank you for] providing my son with this program. I hope this program stays intact forever because I think it’s incredibly helpful and it gives these kids/adults much needed confidence to be independent. Thank you for allowing my son to be a part of this program it has changed his life for the better.”

“I couldn't be more enthusiastic about SDP. It has completely changed the life of my identical twin daughters. It has created a personalized program for them that has provided the support that they need to thrive in their life. They have I/DD and seizures and without the continuity and consistency of the staff that is familiar with them and their uncontrolled seizures, they would not be so integrated in their community. They have so much choice in what they pursue, from volunteering to supported employment, music enrichment, personal training, and nutrition planning/cooking classes. They have never been so happy, and I could never have dreamed they would have the necessary, comprehensive support to live as independently as they do. Being around anyone who is doing what they love has a positive ripple effect. The growth we have seen in our daughters in the 3 years of SDP has blown us away. They are more confident, have a more positive outlook and have an enhanced quality of life.”

“I have autism and schizophrenia. I was not able to fit in at any community program. All they did was drag me to malls and stores every day. Now I have a program through SDP that has made my life very happy. I can have my own helpers. I am a painter, and I have a micro business where I show my art and I sell it on a website, which I'm very happy about. [SDP] made my life so much better. I go to the gym, I go to the beach. I go a lot of places. It has been a godsend, and I can't imagine life without it.”

“The SDP has been enormously beneficial for our son. We are incredibly grateful for the SDP. There have been so many positives for our son around health, wellness, independence and community engagement. He is building relationships and friendships and growing confidence in his abilities. His quality of life, at age 26, is the best it has ever been thanks to the SDP program and what it has made possible for him.”

From the Perspective of SDP Professionals

People who serve the community of people with intellectual/developmental disabilities have a unique perspective on the impact and importance of the SDP. Some of these professionals shared their thoughts and experiences on behalf of those that they serve.

“I was part of a project [between the local SDP advisory committee and my Family Resource Center] to help families in the Self-Determination Program. After the project was completed, we saw that there was still a need, so we continue to have core group meetings and in-person meetings with anyone who had questions. One of the families that was referred to us had questions about where to start and where to go, so I invited her to one of these meetings. She was able to meet [people in] different roles such as community-based organizations, vendors, Financial Management Services, Independent Facilitators, and other self-advocates that are in the SDP, and she got to hear a lot about how the services work - the good and the bad. She [connected] with an FMS that helped her start the process to onboard her child. She's very happy about the services that she has for her child now because they're able to create the schedules and hire the people they need for her child. I'm hearing from other self-advocates and parents who participate in our Self-determination meetings that they're enjoying the freedom and flexibility. We need to continue the service to help those that are enjoying the service.”

“I am currently in the sixth year of the Self-Determination Program and am also an independent facilitator and work exclusively with the Hispanic community in California across ten regional centers throughout the state. Through the Self-Determination Program, my family and I were able to truly create a plan centered on my child's needs - culturally sensitive and focused on safety and quality of life in the community. This is not a luxury; it was a need that was not being addressed in the traditional system. The program empowers Latino families and reduces inequality in access to services. I have seen clients integrated into the community with one-on-one services, inclusion, and fulfillment of the rights guaranteed under the Lanterman Act.”

“I am writing to share the profound and measurable impact the Self Determination Program has/had on the individuals I have had the pleasure of supporting over the years. This program is unequivocally valuable. It provides people with disabilities the space, autonomy, and resources to develop their personal interests and explore the opportunities that every person deserves access to. Rather than being confined to a limited, pre-designed pathway, participants are empowered to define their own goals and pursue lives that are

meaningful to them. I have seen this program positively impact every individual I serve, witnessing their personal growth as they move through some of life's biggest challenges (living independently, gaining and sustaining employment, financial literacy, pet ownership, and developing lasting relationships with friends and significant others). It creates real opportunities for personal growth and meaningful contribution. Importantly, these contributions are not limited to what society traditionally expects or deems useful. They are contributions that matter deeply to the individual and are rooted in dignity, choice, and purpose. Our communities benefit as well. When individuals with disabilities are supported in pursuing their goals communities grow in empathy and understanding. They learn from this example of seeing first-hand what is possible when people are given the appropriate support to thrive. The Self Determination Program helps shift the narrative from limitation to capability. It builds equity by ensuring individuals are not placed into narrow categories designed only to make them more "socially acceptable," but instead are supported in discovering their true gifts, passions, and drive for evolving their lives to be a true reflection of who they are. This program is not simply a service model; it is a commitment to equity and autonomy. It reflects the belief that society should rise to meet individuals where they are, not require them to shrink themselves to fit outdated systems. It matters deeply to me that this program continues to be supported and strengthened so that many more will come to discover their life's purpose. Its impact is tangible. It is transformative. This is essential for building communities that value dignity, opportunity, and meaningful participation for all."

"SDP has been a game changer for my daughter's life. To be able to use her funds to move her towards a life of independence and skills for work. It has also provided her with training for her personal health and safety, and with skills to build relationships. It's made her life rich, full, and meaningful."

Other Feedback on the SDP Waiver

Families also provided the feedback below to be included as additional comments on the SDP Waiver Renewal:

"Thank you for the opportunity to provide feedback on the Self-Determination Waiver Application. As a family of an adult who is medically complex and has high support needs, we strongly support continued federal funding and a strong waiver that preserves the flexibility that makes SDP work. Some additional thoughts:

1) Innovate for people who don't fit traditional programs: Many individuals, especially those who are medically complex or have high support needs, do not qualify for, or are not well served by, traditional adult day programs. Without alternatives, they are at real risk of being isolated at home. This is the challenge our family faced. One of SDPs greatest strengths is that it can fund individualized, community-based supports and allow families and providers to pilot creative models that would not otherwise be tried. The waiver should protect this flexibility and explicitly support the ability to use SDP to develop and test new approaches that meet the needs of people who fall outside standard program categories.

2) Housing choice: Families need a spectrum of integrated housing choices after the post-school transition besides putting people into licensed homes. For example, neurotypical young adults commonly live in dorms, shared houses, or even sorority/fraternity houses after graduating from high school; young adults with disabilities should have comparable, home-like shared living options. The focus should be on whether a setting is truly home-like, protects individual rights and autonomy, and supports full participation in community life -- not simply whether the residence is shared or how many housemates live there. Otherwise, by limiting ordinary housing choices for people with IDD you are discriminating against them.

3) Make SDP workable in real time: Timely onboarding and payment processes are essential, especially since it involves CA employees getting paid appropriately and on time for services rendered. But whether an FMS can deliver on this is difficult for a consumer to know beforehand. Because FMS usability and quality vary widely, DDS should provide a consumer-friendly way to compare FMS providers (similar to Yelp) where participants and families can submit one-star ratings and written comments based on their lived experience. Ideally, DDS could also include a few standardized metrics (e.g., avg onboarding timelines, payment timeliness, portal and app usability, and customer support

responsiveness) so ratings are comparable and actionable. This would help participants make more informed choices among FMS providers and create strong incentives for continuous quality improvement on the part of the FMS's."

"We need to review Facilities as it is my experience for my loved one that undue influence and isolation and even restraints - which could be seen as false imprisonment as stated under PC 236 - may occur time to time when staff holds a resident when the person wants to visit. [I hope for] better monitoring but know the limited personnel make this challenging. Also, for the general living area maybe cameras to monitor to avoid abuse. Licensing seems to need to be present when an event occurs to hold believe by a resident or observer. SDP would reduce facility needs and increase independence of the member or resident."