

NOTICE/AGENDA

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES COUNCIL MEETING

This meeting is being held via teleconference within the meaning of Government Code section 11123.2. Members may be physically present at one or more teleconference locations. There may be members of the public body who are participating in today's meeting that were granted a reasonable accommodation per the Americans with Disabilities Act (ADA). Accessible formats of all agenda and materials can be found online at www.scdd.ca.gov

MEETING DETAILS:

JOIN BY TELECONFERENCE:

MEETING ID: 880 9133 4412

(877) 853-5257

CALL IN NUMBER: (888)-475-4499 or

TELECONFERENCE LOCATION:

SCDD HQ OFFICE 3831 North Freeway Blvd., #125 Sacramento, CA 95834

JOIN BY ZOOM:

https://bit.ly/SCDDCouncilJuly2024

MEETING ID: 880 9133 4412

PASSCODE: 312507

DATE: July 16, 2024

MEETING TIME: 10:30 AM – 3:00 PM

COUNCIL CHAIR: Wesley Witherspoon

Item 1. CALL TO ORDER

Item 2. ESTABLISH QUORUM

Item 3.	SWEARING IN OF NEW COUNCILMEMBER	Page 4
Item 4.	WELCOME AND INTRODUCTIONS	
Item 5.	PUBLIC COMMENTS This item is for members of the public to provide comments and/or present information to this body on matters not listed on the agenda. There will be up to 20 minutes allocated to hear from the public with each person allotted up to 3 minutes to comment.	
	Additionally, there will be up to 10 minutes allocated to hear from the public Council agenda item, with each person allotted up to 1 minute to comment.	on each
Item 6.	APPROVAL OF MAY 2024 MINUTES VMTE All	Page 6
Item 7.	CHAIR REPORT AND COMMITTEE REPORTS Wesley Witherspoon, Council Chair	Page 20
	A. Membership Committee Report B. Employment First Committee (EFC) C. Administrative Committee D. Executive Committee E. State Plan Committee (SPC) F. Statewide Self-Determination Committee (SSDAC) G. Self-Advocates Advisory Committee (SAAC)	
Item 8.	EXECUTIVE DIRECTOR REPORT & STAFF REPORTS Aaron Carruthers, Executive Director	Page 27
	 A. Chief Deputy Director Report B. Deputy Director of Policy and Public Affairs Report C. Deputy Director of Regional Office Operations Report D. CRA/VAS Report E. QA Project Update Report 	
ltem 9.	STATEWIDE SELF-ADVOCACY NETWORK (SSAN) REPORT SCDD SSAN Representative Alex Reyes	Page 56

Item 10. UPDATES ON THE LANTERMAN ACT

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Will Leiner, Disability Rights CA Vivian Haun, Disability Rights CA

Item 11. CYCLE 47 GRANT PROPOSALS VMTE

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Rihana Ahmad, Manager - HQ Operations & State Plan Michael Ellis, State Plan Committee Chair

Item 12. PERSON-CENTERED THINKING

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Evan Barnwell, Self-Advocate Viviana Barnwell, Councilmember

Item 13. HISTORY OF PEOPLE FIRST

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Rosie Ryan, Councilmember

Item 14. NEXT MEETING DATE AND ADJOURNMENT

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The next Council meeting will be in person on September 24, 2024.

Accessibility:

Pursuant to Government Code Sections 11123.1 and 11125(f), individuals with disabilities who require accessible alternative formats of the agenda and related meeting materials and/or auxiliary aids/services to participate in this meeting should contact Yaritza Sanchez at (916)-207-2856 or yaritza.sanchez@scdd.ca.gov. Please provide at least 3 business days prior to the meeting to allow adequate time to respond to all requests.

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

AGENDA ITEM 3. INFORMATION ITEM

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Swearing in of New Councilmember

Executive Director Aaron Carruthers will swear in new Councilmember Lupe Rodriguez.

AGENDA ITEM 5. INFORMATION ITEM

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Public Comments

This item is for members of the public to provide comments and/or present information to this body on matters not listed on the agenda. There will be up to 20 minutes allocated to hear from the public with each person allotted up to 3 minutes to comment.

Additionally, there will be up to 10 minutes allocated to hear from the public on each Council agenda item, with each person allotted up to 1 minute to comment.

AGENDA ITEM 6.

ACTION ITEM

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Approval of May 2024 Minutes

The draft minutes from the May 21, 2024, Council meeting have been included in the packet for review. Councilmembers will vote on whether to approve the minutes.

Attachment

May Council Meeting Minutes

Action Recommended

Approve the May 2024 Council meeting minutes.



DRAFT Council Meeting Minutes May 21, 2024

Members Attending

Alex Reyes (S.A.) Aubyn Stahmer (UCEDD) Beth Stoffmacher (UCEDD) Cathay Liu (F.A.) Eric Ybarra (S.A.) Harold Ashe (F.A.) Harold Fujita (F.A.) Jessica Brown (F.A.) Jessica Grove (DOR) Joseph Billingsley (DHCS) Joyce McNair (F.A.) Julie Neward (F.A) Julio Garnica (S.A.) Kara Ponton (S.A.) Lee Bycel (F.A.) Nestor Nieves (S.A.) Nicole Adler (S.A.) Sandra Smith (DRC) Sonia Jones (S.A.)

Wesley Witherspoon (S.A.)

Members Absent

Brian Winfield (DDS)
Debra Cooper (CHHS)
Julie Gaona (S.A.)
Larry Yin (UCEDD)
Mark Beckley (CDA)
Michael Ellis (F.A.)
Rosanna Ryan (S.A.)
Viviana Barnwell (F.A.)

Others Attending

Aaron Carruthers Beth Hurn **Brian Weisel** Carla Castañeda Carmela Garnica Catherine Blakemore Chris Arroyo Christine C. Tolbert Charles Nguyen David Grady Debra Adler **Debra Ponton** DeLois McGriff Dena Hernandez Fatima Mohammadi Holly Bins

Others Attending (cont.)

Ibrahim Muttaqi Julie Eby-McKenzie Ken DaRosa Kristie Allensworth Lisa Hooks Lynn Villoria Mary Ellen Stives Maureen Fitzgerald Michelle Cave Natalie Payne Nicole Patterson Patricia Herrera Peter Mendoza Renee Bauer Riana Hardin Rihana Ahmad Robin Maitino-Erben Rondale Holloway Rosemary Payne Rihana Ahmad Scarlett VonThenen Sheraden Nicholau Tania Morawiec Thuy Le Yaritza Sanchez Yolanda Cruz

1. CALL TO ORDER

Nick Wavrin

Chair Wesley Witherspoon called the meeting to order at 10:33 A.M.

2. ESTABLISH QUORUM

A quorum was established.

3. WELCOME/INTRODUCTIONS

Members and others in attendance introduced themselves and disclosed if there were others in the room with them.

4. PUBLIC COMMENTS

Debra Adler provided a public comment regarding her experience with the Self Determination Program. She described the program as both a blessing and a curse. The blessing was that her daughter Nicole thrived under the program, particularly with the support of her service dog, Ruby. However, the curse was the administrative and financial difficulties she faced. Despite having a spending plan approved in September 2023 with \$14,000 allocated for Ruby's expenses, the Golden Gate Regional Center and GT Independent had not processed any payments for these costs. As of May 20th, Debra had paid out of pocket for all related expenses and encountered significant delays and lack of communication from both agencies. Her efforts to resolve the issues, including multiple spending plan submissions and requests for fund transfers, went unanswered. This lack of support resulted in the loss of Nicole's care providers, who quit due to non-payment. Debra expressed her frustration with the lack of support and responsiveness from the involved parties. Despite her struggles, she acknowledged the potential benefits of self-determination but highlighted the severe systemic issues she faced.

Manager of the North Valley Regional Office, Dena Hernandez, provided a public comment. She expressed gratitude to the Council for their sponsorship of the Choices Institute's 2024 conference, held on April 12th at the San Joaquin County Office of Education. The sponsorship contributed to the success of the event, which was sold out with 500 attendees. The conference featured three keynote speakers who were adults with developmental disabilities, sharing their personal stories. The event's theme was "Be the light. Share your light through your choices." Dena also presented a T-shirt, a certificate of gratitude, and a sizzle reel video created by students from Future Films, which captured highlights of the conference and showcased its impact.

Rosemary Payne, the mother of Councilmember Julie Neward and selfadvocate Natalie Neward, provided a public comment. As a retired registered nurse, Rosemary had spent 43 years providing full-time care for Natalie, who was born in 1982 and later suffered from acute cerebellar ataxia twice. This condition led to severe health complications, including a 3-month coma and status epilepticus. Her care included emergency helicopter transfers to UCSF due to severe apnea. A breakthrough came in the early 1990s with the introduction of Depakote sprinkles, which significantly improved Natalie's condition. Despite her professional background, Rosemary found the medical and support systems overwhelming and often learned about available services through changes in regional center social workers. Currently, they benefit from self-determination, although they face challenges with the time clock system causing repeated overtime payments. Lastly, she expressed gratitude for the Council's work, enabling families to voice their concerns, and highlight the in-home support services and accommodations they have received.

5. APPROVAL OF MARCH 2024 MINUTES Action 1

It was moved/seconded (Ybarra [S.A]/ Reyes [S.A.]) and carried to approve the March 2024 meeting minutes as presented by unanimous acclimation. (See last page for a voting record of members present)

6. CHAIR REPORT AND COMMITTEE REPORTS

Chair Witherspoon provided an update on his recent activities, and priorities for the Council. He highlighted May as Mental Health Awareness Month, which had been observed in the US since 1949. It was intended to increase awareness about how mental health plays a role to our overall well-being and to provide resources to support those in need. The Chair encouraged attendees to engage in activities like guided meditation and outdoor wellness and to check in on their friends and family. He then highlighted the Council's Storytellers Blog, which featured stories from self-advocates in the community. Recent blog posts highlighted Councilmembers Alex Reves and Rosie Ryan, with Reves discussing his journey with self-advocacy and music and Ryan sharing her experiences in the school system as a person with a disability. He encouraged everyone to visit the Council's website to read the blogs. Next, he introduced Jay Nolan Community Services, a nonprofit organization founded in 1975 by members of the Autism Society of LA. The organization supports individuals with Autism and other developmental disabilities to live fulfilling lives through customized support services. Jay Nolan Community Services operates in LA, Ventura, Kern, and Santa Clara Counties, providing services such as Supported Living, Family

Support, and Employment Services. The Chair, who worked as an independent contractor for the organization, shared a video about their work, https://www.viewpointproject.com/features-jay-nolan-community-services/.

He also provided an update on the Disability Policy Seminar held in Washington DC from April 8-10th. The seminar addressed various policy issues affecting the disability community, including the direct care workforce crisis and the Autism CARES Act. Attendees also received training on effective advocacy storytelling. The Chair shared photos from the event, featuring his U.S. Representative Congresswoman Maxine Waters and other attendees. Next, the Chair discussed a meeting with the Governor's office, where Councilmembers expressed their concerns about the proposal to delay the full funding of rates to July 2025 instead of July 2024. Despite the budget deficit, the Council highlighted the adverse effects the delay would have on individuals with developmental disabilities. He thanked the participating Councilmembers and acknowledged the Governor's continued support. Lastly, the Chair shared some personal photos from his trip to Disney World and Universal Studios with Councilmember Gaona and her husband Rigo.

SCDD committee reports were provided in the meeting packet. Chair Witherspoon asked that members read through these reports when they are able. The committee reports can be accessed online at https://scdd.ca.gov/councilmeetings/.

7. EXECUTIVE DIRECTOR REPORT AND STAFF REPORTS

The Executive Director presented an overview of his report, covering updates on advocacy, the 504 final rule, the self-determination program, and various announcements. He emphasized the house of origin deadline on Friday, May 24th, requiring bills introduced by a Senator to be passed by the Senate and those introduced by an Assemblymember to be passed by the Assembly. The Assembly had 553 bills and the Senate had 365 bills on the floor, for a total of 918 bills to be considered.

Several bills supported by the Council were highlighted under the themes of health, home, and work. Under the health theme, AB 1977 (Ta) aimed to reduce healthcare coverage recertification barriers for individuals with developmental disabilities. SB 1384 (Dodd) allowed individuals to repair their own power wheelchairs, while SB 1001 (Skinner) intended to protect individuals with intellectual disabilities from the death penalty. All these

bills were active and progressing through the legislature. For the home theme, SB 1443 (Jones) proposed adding the State Council to the Interagency Council on Homelessness. AB 1876 (Jackson) aimed to allow Individual Program Plans (IPPs) to be conducted remotely. SB 1281 (Menjivar) addressed improves the Self-Determination Program, based on the Council's evaluation from the previous year. Under the work theme, AB 1885 (Addis) proposed that nine units be considered full-time for students with disabilities. However, AB 2753 (Ortega), which aimed to cover durable medical equipment, was held in the appropriations suspense file due to high costs.

During the advocacy update, the Executive Director announced several proposals from the Governor aimed to support the State Council and its administration. One proposal included the addition of a Staff Support Assistant to support employees with intellectual, developmental, or other disabilities to succeed in their roles as professionals. The Governor also proposed that the State Council receive permanent staff for Self-Determination orientation trainings and the statewide Self-Determination Advisory Committee. Furthermore, the proposal included budget authority for the State Council to continue spending grant funds on providing gokits for emergency preparation plans. The Executive Director expressed appreciation to Chief Deputy Director Ken DaRosa, Budget Officer Lynn Villoria, and the Governor for their efforts in advocating and advancing these proposals to the legislature for consideration.

The Executive Director then addressed the update on the section 504 final rule. Section 504 of the Federal Rehabilitation Act prohibits discrimination on the basis of disability in programs and activities receiving federal funding from the Department of Health and Human Services (HHS). On May 1st, HHS finalized a rule to strengthen protections for individuals with disabilities. The rule aimed to prevent medical decisions from being based on biases or dehumanizing beliefs and bans "value of life" assessments for determining eligibility for care or benefits. Additionally, the rule defined accessibility standards for websites and mobile apps and adopted standards for medical diagnostic equipment, such as exam tables and mammogram machines. The Administration on Community Living (ACL) recognized the new rules, stating that they were a direct result of decades of advocacy by people with disabilities and was one of the strongest tools available to combat discrimination.

Executive Director Carruthers provided an update on the Self-Determination Program (SDP), reporting that 4,200 people were participating as of March 2024. A bar graph was presented showing the number of SDP participants by Regional Center. The graph revealed notable disparities among regional centers. San Diego Regional Center, with the second-largest consumer base, had the highest number of SDP participants, while Inland Regional Center, with the largest consumer base, had a relatively lower number of participants. Smaller centers like Redwood Coast had fewer SDP participants, consistent with their overall consumer numbers, but others like Far Northern showed disproportionately high participation. Another bar graph compared SDP participants to overall regional center consumers by ethnicity. The graph revealed that Asian and White consumers were overrepresented in SDP, while African-American, and Hispanic consumers were underrepresented. The "other" category showed proportional representation. These trends highlighted ongoing disparities and the need for continued monitoring and addressing equity in program participation.

Furthermore, the Executive Director highlighted an article in the Los Angeles Times that featured the Council's work. The article, "People with disabilities love this program. Why are Latinos underrepresented?", was published on April 15, 2024. It was based on the Council's evaluation of the Self-Determination Program that was presented at the July Council meeting and cited SB 1281 (Menjivar); a bill supported by the Council. This legislation, sponsored by ICC and DVU, aimed to reform the Self-Determination program based on the evaluation's evidence. The Executive Director was quoted in the article, noting that the higher spending plans in the Self-Determination Program (\$38,000) compared to the traditional system (\$34,000) were a sign that underserved individuals were finally receiving needed services. He explained that the Self-Determination Program allowed for more flexible service provision, permitting individuals to find non-vendored services when traditional vendors are unavailable. This flexibility addressed unmet needs and results in higher costs, which he viewed as a positive outcome. He countered criticisms about the program's costs, arguing that the increased spending reflects better service provision and improved outcomes for those previously underserved by the traditional system.

The Executive Director commended Christine Tolbert for her outstanding work in the Self-Determination orientation training program. From July 2022 to March 2024, Christine conducted 214 training sessions attended

by over 4,800 participants. These sessions were delivered in ten different languages. Feedback from attendees was highly positive, with 90% indicating that they found the information useful. Regarding future enrollment in the Self-Determination Program, 69% of participants expressed their intent to enroll, 22% were undecided, and 5% did not plan to enroll. He also shared his recent participation at the 50th People First Conference in Anderson, CA, with Councilmember Rosie Ryan. The conference celebrated over 200 years of the self-advocacy movement in California. The conference theme, "Ohana means family," highlighted the values of inclusivity and community. The event featured high quality presentations and fostered a strong sense of community among participants.

The Executive Director then shared that the federal government had successfully passed its budget for the fiscal year October 2023-September 2024, which included level funding for Councils. This meant that California would receive the same funding as in the past four years. He pointed out that while it was good news that there were not budget cuts, the unchanged funding amount was challenging due to inflation and rising costs, effectively reducing what could be accomplished with the same budget. Lastly, he introduced the new Personnel Officer, Thuy Le, and mentioned that the Council's Attorney, Brian Weisel, will leave at the end of May. He also noted the continued recruitment for Deputy Director of Policy and the Council's Attorney.

8. SCDD 2024-2025 BUDGET

Carla Castañeda, the Chief Deputy Director from the Department of Developmental Services, presented updates on the Governor's May Budget Revise. She provided a comparison of the current year's (2023-2024) budget with the next year's (2024-2025) budget projections. She highlighted a slight reduction in the projected purchase of services (POS) for the current year due to the budget deficit. Despite this, the overall budget for the current year was still projected to be \$11.5 billion, growing to \$13.3 billion in the next fiscal year.

For Regional Center operations, there was an increase from \$1.4 billion to \$1.5 billion. The state-operated services budget, which includes Porterville STAR Homes and community facilities, showed an increase due to a \$20 million drop in the current year caused by vacancies in the first half of the fiscal year. For DDS headquarters support, a decrease reflected one-time funding for IT projects and other augmentations. These

budgets were projected to support a regional center caseload growing from 429,000 individuals in the current year to approximately 465,000 individuals in the next budget year.

She also provided a reminder about the American Rescue Plan Act, also known as the Home and Community-Based Services (HCBS) spending plan. She noted that the initiatives under this plan had mostly remained the same over the three-year period, with increases and adjustments related to the purchase of services and reimbursement rates. The recent May revision revealed that additional HCBS funds were available, which could be utilized on the DDS side of the budget. This did not alter the overall budget but impacted the distribution of HCBS funding. She also highlighted the American Rescue Plan Act dollars that were part of the Early Start grant. There were no changes in the May revision for these funds, but she emphasized the importance of these initiatives as they were separately funded and tracked.

Ms. Castañeda provided a summary of the current year's projections. She noted that there were no projected changes in the caseload, which resulted in no changes to regional center operations despite variations in service utilization. Declines were noted in most service categories, but there were increases in in-home respite transportation and some Early Start services. For the upcoming budget year, a projected increase of almost 7,000 individuals compared to the Governor's budget will lead to a slight increase in the overall budget for the purchase of services. The active Lanterman population (ages 3 and over) was expected to increase, with a slight decrease anticipated in the Early Start program compared to the Governor's budget. Provision eligibility was not expected to change, though it may result in more children from the Early Start program, now including ages 0 to 2.

She also outlined the May revision's general fund solutions aimed at achieving a balanced budget to address the \$27 billion deficit. The proposed reductions in the DDS budget include delaying the service provider rate reform to July 1, 2025, and extending the delay for preschool inclusion grants by an additional two years. The revision also introduced four additional items: First, the internship program, a \$22.5 million workforce stability initiative, that will see a reversion of \$20 million. Though it would still allow current participants to continue their internships. Second, the health and safety waiver assistance will be eliminated, although regional center plans supported by language access

and cultural competency initiatives may offset some challenges. Third, the emergency preparedness resources, which involves regional emergency coordinators, will no longer receive equipment and material funding, but other local federal resources will be utilized for needs like go-kits and battery backups. Lastly, the tribal engagement and outreach program, which was proposed to expand, will maintain its current \$500,000 funding level for three regional centers. She concluded her updates by reminding attendees that the Master Plan for Developmental Services was ongoing, with a report deadline set for March 2025.

Executive Director Carruthers then presented updates to the 2024-2025 SCDD budget shared in March 2024. He relayed that the basic state grant and the Client's Rights Advocacy/Volunteer Advocacy Services (CRA/VAS) budgets, led by Holly Bins, remained unchanged. However, the Quality Assessment Project budget, led by Ruby Villanueva, increased by \$233,000 due to a new three-year agreement with the Department of Developmental Services, which increased operational costs for the national core indicator survey. The Self-Determination Technical Assistance Program (SDM-TAP) budget, led by Hannah Dunham, reflected the \$5 million allocated at the start of the fiscal year 2024-2025, with most funds awarded as grants and some remaining administrative funds. For the Supportive Decision-Making Technical Assistance Program, \$1,462,000 remained available, an increase of about a million dollars from what was presented in March. He provided a summary of the proposed budget for the upcoming fiscal year, beginning July 1st. The budget included \$8,102,000 for federal dollars (the basic state grant), \$4,017,000 for the quality assessment contract, \$1,694,000 for the Client's Rights Volunteer Advocacy state contract, and \$1,462,000 remaining for the Supportive Decision-Making Technical Assistance Program. Staff requested the Council to approve a total budget of \$15,275,000 for the next fiscal year.

Action 2

It was moved/seconded (Ybarra [S.A]/ Ponton [S.A.]) and carried to adopt the 2024-2025 SCDD Budget as presented. (See last page for a voting record of members present)

9. PERSON-CENTERED THINKING

The Chair announced that item 9 would be postponed to a future meeting date as Viviana and Evan Barnwell were unable to attend the Council meeting.

10. MASTER PLAN DISCUSSION

Catherine Blakemore, with California Health and Human Services Agency, provided an overview of the Master Plan for Developmental Services. She relayed that the plan aims to create a system that offers equitable, consistent, and accessible services to Californians with developmental disabilities. Its target completion date is March 2025, and under the direction of Secretary Gally. The plan involves collaboration with numerous partners and stakeholders statewide.

The plan focuses on modernizing the service delivery system to provide comprehensive, high-quality care throughout all stages of life and across different communities. This involves integrating services such as IHSS and Medi-Cal more effectively to streamline support for individuals with developmental disabilities. She clarified that the plan was not intended to cut spending or move services into managed care, but rather to develop long-term goals and recommendations for improving the system over the next five to ten years. The plan will include both long-term recommendations and short-term steps, similar to the Master Plan for Aging, and will be revisited every two years to evaluate progress and set new objectives. The plan is guided by a committee of 37 diverse experts, including those served by regional centers, family members, advocates, policy experts, and service providers. To ensure broader input, the plan will incorporate community feedback through focus groups, round tables, and public comment periods during meetings. She also announced the formation of five work groups, each focusing on different priorities. The California Health and Human Services website will provide the application to join the work groups and a platform for public input. She encouraged attendees to get involved, either by joining a work group or providing feedback through the website.

Next, Ms. Blakemore discussed the vision statement, stating that all individuals and families should receive high-quality, person-centered services. She stressed the importance of meeting basic needs to allow individuals to live in their community of choice, addressing challenges like affordable housing and safe residential options. She highlighted the goal of creating seamless service systems, ensuring access to necessary services without concern over which agency or funding source provides them. Services should be equitably available regardless of location or provider, and systems should be transparent, accountable, and data driven.

Catherine asked members to share their vision for the future of the developmental disability service system. Councilmember Julie Neward spoke about using technology, such as the LucIDD app, to monitor and manage her sister's health, expressing concerns about medical needs and over-prescription issues. She highlighted the app's capability to alert healthcare providers and caregivers, thus improving care and reducing costs. Councilmember Sandra Smith pointed out the need to address diverse equity issues, and Councilmember Sonia Jones raised concerns about the financial burden of copays for Medi-Cal. Councilmember Harold Fujita focused on accountability, advocating for transparency in service delivery and the true cost of system failures or successes. Councilmember Kara Ponton suggested training modules for healthcare providers, and Councilmember Joyce McNair stressed the importance of system integration to avoid issues like excessive copays. Councilmember Lee Bycel highlighted the ongoing issue of budget constraints and emphasized the importance of effectively communicating the experiences of the IDD community to the public. He suggested involving the private sector, which has significant resources, to make the vision more actionable. Councilmember Eric Ybarra discussed challenges with copays and how regional centers provided unexpected solutions to deliver his medications. Councilmember Nestor Nieves highlighted the importance of reaching out to underrepresented communities, and Councilmember Alex Reves emphasized the need for plain language. Councilmember Joyce McNair pointed out the need for better integration of services for those with both developmental and mental health diagnoses. Councilmember Sonia Jones raised the issue of credit checks for low-income housing. Council Chair Wesley Witherspoon discussed the needs of aging individuals with complex medical conditions. Councilmember McNair also emphasized the need for better support for aging parents of children with IDD.

Catherine asked Councilmembers to provide advice on the key priorities for the Master Plan committee. Councilmember Joyce Mcnair suggested that the committee focus on short-term solutions that could be implemented within the next year or two. Councilmember Julie Neward shared her personal experience as a sibling of a person with disabilities, highlighting the significant life changes she has undergone. She mentioned the SibShop program in Washington State and advocated for the establishment of sibling support groups in schools across the country. She stressed the need for lifelong support for siblings who often become primary caregivers. Council Chair Wesley Witherspoon emphasized the

necessity of supporting caregivers, such as nurses, teachers, and siblings, noting that parents will eventually pass away.

Maureen Fitzgerald provided a public comment, drawing on her extensive experience in the field, including volunteering at Napa State Hospital. She emphasized the importance of examining relevant data and shared her findings from a public records request regarding Regional Center spending per person. In the 2022-23 fiscal year, Golden Gate Regional Center spent \$27,000 per consumer, while other centers spent about \$14,000, with a statewide average of \$18,000 for 473,000 individuals. Maureen highlighted the disparity in spending and its connection to equity, noting that while spending does not need to be identical, such large gaps were concerning. Additionally, Maureen stressed the need for service coordinators' voices to be included in the Master Plan discussions. She described service coordinators as the backbone of the system, with firsthand knowledge of its challenges and strengths. Maureen recommended that the Master Plan committee actively seek the involvement of service coordinators to identify what is and isn't working at regional centers and how families could better engage with the system.

Debra Adler provided a public comment expressing her gratitude for the presentation and her anticipation of the outcomes from the Master Plan and budget. She echoed Councilmember Julie Neward's concerns about isolation, emphasizing that she, too, feels completely isolated, as does the person she cares for. Debra shared her personal experience, highlighting the importance of planning for the future. Debra pointed out that the life expectancy of people with Down's Syndrome had significantly increased over the past decades, requiring more thorough and forward-thinking planning.

11. **NEXT MEETING DATE AND ADJOURNMENT**

The next Council meeting will be held on Zoom on July 16, 2024. Chair Witherspoon adjourned the meeting at 3:20 P.M.

Name	Action 1	Action 2
Adler, Nicole	For	For
Ashe, Harold	For	For
Billingsley, Joseph	For	For
Brown, Jessica	For	For
Bycel, Lee	For	For
Fujita, Harold	For	For
Garnica, Julio	For	For
Grove, Jessica	For	For
Jones, Sonia	For	For
Liu, Cathay	For	For
McNair, Joyce	For	For
Neward, Julie	For	For
Nieves, Nestor	For	For
Ponton, Kara	For	For
Reyes, Alex	For	For
Smith, Sandra	For	For
Stahmer, Aubyn	For	For
Stoffmacher, Beth	For	For
Wavrin, Nick	NP	For
Witherspoon, Wesley	For	For
Ybarra, Eric	For	For

AGENDA ITEM 7. INFORMATION ITEM

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Chair Report and Committee Reports

Council Chair Wesley Witherspoon will provide Councilmembers with an oral report about his recent activities, and current priorities for the Council.

SCDD Committee reports have been provided for informational purposes.

Attachments

Membership Committee Report to Council

The Employment First Committee met on 05/16/24.

The Administrative Committee met on 05/30/24.

The Executive Committee met on 06/18/24.

The State Plan Committee (SPC) met on 06/27/24.

Handouts

The Statewide Self-Determination Committee (SSDAC) will meet on 07/10/24. The Self-Advocates Advisory Committee (SAAC) will meet on 07/15/24.



July 3, 2024 Membership Committee Report to the Council

SEC 1. Existing Vacancies

Seat	Date Seat Became	Months Vacant	
	Vacant	Asterisk (*) indicates vacancy of more than 4 months	
North Valley Hills Region	December 2023	*	

SEC 2. Expired Appointments

Seat	Date Appointment Expired Number of Months Expired Asterisk (*) indicates eligible for reappointment
None	

SEC 3. Upcoming Terms Set to Expire

Seat	Date Appointment Will Expire	
	Asterisk (*) indicates eligible for reappointment	
Los Angeles Region	9/16/2024	
Sequoia Region	9/16/2024	
Central Coast Region	9/16/2024	
At Large	9/16/2024	
At Large Institution	9/16/2024	

SEC 4.	Recommendations Solicited			
Has a solici		ıltiple recommendat	ions for Council appointm	ent been
⊠ Ye	es	□ No		
Agencies Solicited			Date	
SCDD Website			Continuous	
SEC 5.	Counciln	nember Terms		
Appointme	nt Roster Lis	ting Each Members	Term Attached?	
□ Ye	es	⊠ No		

SEC 6. Nominees

Number of candidates forwarded to the Governor's Office for consideration: 1 (North Valley Hills)

AGENDA ITEM 7B.

EMPLOYMENT FIRST COMMITTEE SUMMARY

Date of Meeting

May 16, 2024

Meeting's Focus

The Employment First Committee (EFC) met on February May 16th. The focus of the meeting was to review the final draft of the 2023 Employment First Report. This was the last meeting for the EFC under SCDD, as the committee will now be housed under the California Health and Human Services Agency's new Employment First Office.

Deputy Director of Regional Office Operations Tania Morawiec provided members with an update on the continuation of NEON grant activities and informed members about a funding opportunity through the Disability Innovation Fund (DIF). Committee members provided feedback on the topics that should be covered at future Community of Practice sessions, emphasizing the importance of providing education about microenterprises.

Items Acted Upon

- The Committee approved the February 2024 meeting minutes.
- The Committee adopted the 2023 Employment First Committee Report, pending edits that were made during the meeting.

AGENDA ITEM 7C.

ADMINISTRATIVE COMMITTEE SUMMARY

Date of Meeting

May 30, 2024

Meeting's Focus

The Administrative Committee met on May 30th to review proposed updates to the Council's Administrative Policies. Updates have been made to a number of policies to reflect pandemic related practices and changes in statute, along with evolving Councilmember/staff relationships. Review of administrative policies is ongoing.

Members provided feedback, requesting changes to the language of the Tablet Usage and Virtual Meetings policies to ensure that the policies are not written to incorporate a specific tablet brand or virtual meeting platform. Members also requested corrections to grammar and punctuation and asked that staff make any additional grammatical changes as needed, and to make changes to reflect gender neutrality as needed.

Items Acted Upon

- Approval of the February 2024 meeting minutes.
- The Administrative Committee recommended that the Executive Committee approve the proposed changes as discussed and delegate staff the ability make non-substantive grammar changes, including gender neutrality throughout the Councilmember Administrative Policies.

Future Meeting Date

To be determined.

AGENDA ITEM 7D.

EXECUTIVE COMMITTEE SUMMARY

Date of Meeting

June 18, 2024

Meeting's Focus

The Executive Committee met on June 18, 2024. The meeting's focus centered on three sponsorship requests, an SCDD budget update, Executive Director Evaluation process update, the 2023 Employment First Committee Annual Report, and reviewing updates to the Councilmember Administrative Policies. Executive Director Carruthers provided members with a report sharing updates related to the Council's supported legislation and priority items, the full implementation of funding for the rate study, the Governor's proposal to move the Employment First Office to the Department of Rehabilitation, Cycle 47 grants, recent partnerships, and SCDD related announcements.

Items Acted Upon

- Approval of the April 2024 meeting minutes.
- Approval of sponsorship requests from the Arc of CA, the University Center for Excellence in Developmental Disabilities (CEDD) at the Medical Investigation of Neurodevelopmental Disorders (MIND) Institute, and the California Policy Center for Intellectual and Developmental Disabilities (CPCIDD).
- Approval of the 2023 Employment First Committee (EFC) Annual Report.
- Approval of the Administrative Committee's recommendation to update the Councilmember Administrative Policies.

Future Meeting Date

August 20, 2024

Agenda Item 7E.

STATE PLAN COMMITTEE SUMMARY

Date of Meeting

June 27, 2024

Meetings' Focus

The State Plan Committee met on June 27th to review scoring team recommendations for funding Cycle 47 Program Development Grants. The Council received a total of 11 grant applications and recommended funding two projects, one under the focus area of self-advocacy (isolation), and one under self-advocacy (plain language), with a total combined funding amount of \$282,745. Members adopted the scoring team's funding recommendations and sent them to the Council for approval at the July 16, 2024 Council meeting.

The Committee expressed an interest in providing funding for SCDD's Request for Proposal (RFP) under the focus area of Tribal Health. Members discussed the available options and agreed that the committee would like to request that the Council allocate a portion of unexpended funds for a stand-alone Tribal Health RFP, with a project term of 18 months.

Committee members were provided with an update on SCDD's progress toward meeting the 5-year goals set forth in the 2022-2026 State Plan. Due to SCDD's excellent progress, targeted numbers for activities and people reached have been increased for a number of State Plan Objectives.

Items Acted Upon

- The Committee approved the March 2024 Meeting Minutes
- The Committee recommended adoption of the scoring team's funding recommendations and sent them to the Council for approval at the July 16, 2024 Council meeting
- The Committee is requesting additional funding from the Council to relaunch a Cycle 47 RFP with a focus on Tribal Health.

Next Meeting

November 2024

AGENDA ITEM 8. INFORMATION ITEM

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Executive Director Report and Staff Reports

SCDD Executive Director Aaron Carruthers will provide Councilmembers with an oral report regarding recent Council activities. Additionally, SCDD Staff reports have been included in the packet for informational purposes.

Attachments

Chief Deputy Director Report
Deputy Director of Policy and Public Affairs Report
Deputy Director of Regional Office Operations Report
C.R.A./V.A.S. Update Report
QA Project Update Report

Handout

Executive Director Report

Chief Deputy Director's Report: July 2024

The Chief Deputy Director (CDD) continues overseeing operational matters, in concert with staff, and identifying organizational tools to assist the team. Time also has been spent meeting with staff, management, and external partners on various programs, program policy, and implementation, including the Supported Decision-Making Technical Assistance Program (SDM TAP).

Other projects include collaborative conversations with DDS partners regarding the CRA/VAS and QA programs, and other opportunities/project ideas regarding employment and quality assessment surveys. Conversations address funding and contracting matters as well as program efficiencies.

The Chief Deputy Director continues to facilitate and oversee SCDD's administrative functions such as budget management, contracts, and day-to-day operations.

- Continued planning, organizing, and implementation steps with the Supported Decision-making Technical Assistance Program team and external partners. Ongoing efforts included external engagement with partners and pending contractors (e.g., UCLA and UC Davis) finalizing contract scopes of work.
- Reviewed and approved SDM-TAP grant/program support contracts for project evaluation and a resource library.
- Supported the SDM-TAP team in finalizing grant documents and reviewing and approving final grant commitments. As noted in prior reports, the content has been informed by, and responsive to, community conversations

 a series of stakeholder discussions regarding individual and family experience with supported decision making and what was successful and/or challenging for those pursuing or interested in supported decision making.
 Awardees will begin their projects on July 1, 2024.

- Reviewed program and operational contracts for approval.
- Reviewed and approved numerous invoices for program, administrative, and operational services.
- Worked with the budget manager on numerous fiscal matters and reporting (e.g., accounting and expenditure tracking, year-end procedures) and drills from control agencies such as the Department of Finance.
- Concluded contract discussions, with partner agency DDS, on the Selfdetermination Program Orientation and Quality Assurance Project contracts.
 Each of these is a multi-year agreement.
- Continued work on several key recruitments including staff counsel and the Deputy Director for Policy and Public Affairs. Interviews are planned for July. Began recruiting for a new Quality Assessment Program Manager to backfill Ruby Villanueva who will retire at the end of August.
- Completed administrative steps to purchase 1,425 additional go-kits. The kits will be distributed to several regional office beginning in August.

JULY 2024 REPORT FROM THE OFFICE OF POLICY, AND PUBLIC AFFAIRS

POLICY UPDATE

- ✓ **2024 Bills:** The Policy Team continues to monitor all the bills that could affect the I/DD community and continues to review all bill alerts daily. This year's list of bills we support continues to move through the legislation process, with all the bills now in the opposite house (with the exception of 2 bills that failed).
- ✓ 2025 Policy Priorities: We continue to review and research issues brought to our attention. These issues are considered for future policy priorities.
- ✓ **SB 37:** A housing subsidy bill for aging individuals and people with disabilities age 50 and over, continues to move through the legislative process. SCDD is a co-sponsor. Due to the current and growing budget deficit, the bill was amended to reduce its cost from \$500,000 to \$25,000 and made it a pilot program. The bill has passed the Senate and is now in the Assembly. We continue to advocate for the bill in the Assembly Appropriation Committee.
- ✓ Employment First Coalition: In 2023 this diverse coalition championed the creation of the Employment First Office at HHS. We continue to meet on a weekly basis, compiling recommendations, and expertise that we will share with HHS. It is our hope that they will use our recommendations in implementing the new office come July 2024. The coalition has also decided to focus their efforts on creating recommendations for the Master Plan on Developmental Disabilities.
- ✓ Inclusive College Opportunities Coalition (ICA). This year the ICA Coalition successfully advocated for \$2 Million recurring funding for a CA Center for Inclusive College. The Center will connect agencies (DOR, Regional Centers) to college opportunities for students with I/DD. It will also identify best practices for colleges that want to establish inclusive programs and assist with identifying funding sources to establish programs.
 Early this year, the coalition worked with the Governor's staff to include the funding in this year's budget trailer bill. Then May through June, ICA met with legislators to advocate in support of the budget for the Center.
 ICA and our Policy and Communications team will work together to put out a joint press release.

- ✓ **Deaf Steering Committee:** The next Deaf Steering Committee meeting will take place on July 17th. The committee will continue discussions on how to better assist and provide services to clients with hearing disabilities-specifically how to conduct communication assessments and what the standards should be for those conducting the assessments.
- ✓ Federal Public Comment: We submitted public comments for 2 proposed federal rules: 1) In support of proposed rule to implement georouting solutions to 988 Suicide hotline. This would improve the Crisis Lifeline by ensuring calls are routed based on the location of caller and not area code and would connect callers to local support. 2) In opposition to proposed rule to change the transactions involving health care providers, including providers of home and community-based services for people with disabilities. SCDD position is that the potential negative effects will lead to lower health care outcomes for Californians with an intellectual or developmental disability. Without sufficient competition in the health care space, a few dominant providers have leverage to demand price markups, curtailing competition and perpetuating higher prices.

COMMUNICATIONS UPDATE

OUTREACH

- ✓ June News & Events email blast: Included a brief overview about the significance of Pride, how it began and included the 2022 video of Councilmember Adler sharing what Pride means to her. Additional messaging included a link to the history of Juneteenth and ongoing SDP orientations, an in-person SSAN meeting, the Healthy U series finale, and standing SCDD meetings. Messaging was disseminated to over 11,000 unique email addresses, including the CA Legislature via Constant Contact, and shared via the Council's primary social media pages.

- ✓ June Blog Feature Post: "Disabilities and LGBTQ+ Advocacy is All Love" In honor of Pride Month, the Storytellers Blog Page featured a Q&A with SCDD Councilmember, and SF Pride Community Grand Marshal, Nicole Adler. An email blast was sent to nearly 13,000 unique email addresses, including the CA Legislature via Constant Contact, and shared via the Council's primary social media pages. Creative for the rotating banner on the Council's website also used to promote the post.
- ✓ White House Olmstead 25th Anniversary: An email blast with an invitation to the The White House's observance event of the 25th anniversary of the Olmstead Decision which streamed live on Zoom and YouTube. DD Councils and disability advocates were physically present for the event which centered people with intellectual and developmental disabilities. Email blast was sent to over 19,000 unique email addresses, including the CA Legislature via Constant Contact, and shared via the Council's primary social media pages.
- ✓ July News & Events email blast: Included messaging that highlighted Disability Pride Month and ADA Day with a synopsis about the importance of both anniversaries and why the commemorations are held in July. Also included, the National Access and Functional Needs Symposium, an additional SDM-TAP grant opportunity, and SCDD meetings. Messaging was disseminated to over 11,000 unique email addresses, including the CA Legislature via Constant Contact, and shared via the Council's primary social media pages.
- ✓ Interviewed a former Councilmember for a forth coming post for the Storytellers blog page.
- ✓ Participated in legislative outreach planning and coalition meetings.
- ✓ Assisted regional offices, Council committees, and partners with brainstorming, and disseminating information about existing and upcoming initiatives (including webinars and live in-person events) via statewide email or social media.

BRANDING

- ✓ **Completed:** Developed creative for social media banners and a year-long virtual background for Disability Pride Month.
- ✓ In Progress: Researching designs for an annual report template.
- ✓ In Progress: News Release and social media plan for Inclusive College Opportunities Coalition (ICA). To promote the success of securing \$2 Million recurring funding for a CA Center for Inclusive College (CIC).

REPORT FROM: TANIA MORAWIEC DEPUTY DIRECTOR, PLANNING & REGIONAL OFFICE OPERATIONS REPORT RANGE 5/8/24-7/4/24

Activity & Impact

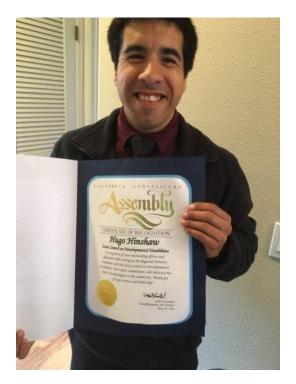
SCDD staff have been focused on technical assistance, community events, and training this reporting period.

- SCDD staff conducted 37 trainings.
- Provided 58 Self Advocate technical assistance services.
- Provided 114 Family Advocate technical assistance services.
- Provided 123 technical assistance services to "other" individuals like professional service providers or educators.

Self-Advocates Recognized for Community Contributions!

 Hugo Hinshaw Honored for Serving on SCDD's Orange County Regional Office RAC

Hugo Hinshaw was formally honored by the Assembly member Josh Lowenthal of the California Legislature for his advocacy and service to the State Council! His hard work, boundless energy, and collaborative spirit helped make the RAC a positive force for improved services for people who have disabilities.





• Councilmember Nicole Adler Rocks the San Francisco Pride Parade!

Councilmember Nicole Adler served as a Grant Marshall in the San Francisco Pride Parade. Her friends and family supported her as well as thousands of parade goers who cheered her on along the route. Nicole is also featured in the SCDD Blog where she shares her thoughts, advice, and ideas on inclusion: <u>Disabilities and LGBTQ+ Advocacy is All Love: An Interview with Nicole "For Love" Adler | SCDD</u>

Q: What message do you have for young LGBTQ+ individuals who may be struggling with their identity or facing discrimination?

N.A.—Educate yourself, attend trainings and webinars, listen to music, find support groups, and read self-care books. Talk to people in your life who can understand you. There are a lot of resources at your local LGBTQ center in your city or county. Don't be afraid to open up. You are not alone!





Project Leadership Training

SCDD's Sacramento Region Manager, Lisa Hooks, is working with diverse community members to build advocacy skills.

What is Project Leadership?

Family Voices of California (FVCA) Project Leadership is a training series for families and caregivers of children and youth with special health care needs (CYSHCN) and disabilities.

Purpose and Support

FVCA advocates for CYSHCN at federal and state levels. CYSHCN are children from birth to age 21 with chronic physical, developmental, behavioral, or emotional conditions needing special services. The Casey Foundation supported the initial development of Project Leadership, and since 2013, the Lucile Packard Foundation for Children's Health has supported its implementation.

Training and Skills

The training provides curriculum, mentorship, information, technical assistance, and systemwide support linkages. It equips families with skills for decision-making and health policy advocacy.

Relevance to SCDD State Plan

Advocacy ensures children receive appropriate care, improving their quality of life and ensuring access to necessary resources and supports in the healthcare and education systems.

Supporting Advocacy

- As parents/caretakers become more proficient in advocating, their confidence grows, enabling them to tackle challenges more effectively.
- The process of advocating teaches resilience and perseverance, as families and caretakers of CYSHCN often must face and overcome barriers.
- Advocacy hones your communication and negotiation skills, which are beneficial in various aspects of life.
- Overall, learning to advocate for the child's special healthcare needs ensures they receive the best possible care and support while fostering the families' or caregiver's own personal and emotional growth.

Supporting Systems Change

- Taking on an advocacy role can position families and caretakers as a leader and a resource within their community, allowing them to support others in similar situations.
- By modeling effective advocacy, families and caretakers can teach their child important self-advocacy skills that will benefit them throughout their life.
- Effective advocacy can contribute to broader changes in policies and practices, benefiting not just a specific child but others with similar needs.

Participants share their thoughts:

- "Project Leadership not only taught me that I have a voice, but it showed me which octave was most effective. In order to advocate for ourselves effectively, we must state our case in a way that appeals to the audience whom we are trying to persuade. The lessons in Project Leadership allowed me to elevate my self-advocacy from a shout to a movement." (Sally S.)
- "My name is Dalton T. my mother, Heidi T. and I participated in the project leadership class with Ms. Lisa Hooks.
 - At first, my mother was present in the class to support myself and my future goals. As the class progressed my mother could not get enough of the content that we were covering as a group. Ms. Hooks has a wonderful teaching style that made a safe and intriguing learning environment, which made my Mother and I comfortable. As a result of how much fun we were having and how much we were learning my mother ended up participating in the full duration of project leadership. I have seen the growth my mother has made since her attendance in the Project Leadership series as she utilized the skills and techniques that Lisa Hooks taught us in class. I would highly recommend and suggest the Project Leadership class to anyone and everyone that would like to further their education in Advocacy and Leadership.

Thank you to the Project Leadership team and to Lisa Hooks for the wonderful opportunity to grow and learn with you."

- "The biggest lesson learned in Project Leadership was to stop apologizing and to convert that into a passionate informed demand for our needs. Lisa showed us how to be informed, prepared and concise. The class is an amazing tool to teach you that perfectly distanced perspective to be able to determine what you actually need vs a muddy cloud of wants and needs and emotions. I have since used the tools in the class to further define what my child needs and how to communicate that with polite but forceful informed language." (Rosanna M.)
- "Thank you so much for the Project leadership training, I truly learned a lot on how the educational system works and how to get my point across in 1 minute. And I even learned the "5 whys". I truly enjoyed taking this training.
- "The Benefit of taking Project Leadership training, is that it helped me how to strengthen my communication skills for when needing assistance in the educational field, as well as understanding how educational laws work. (Jasmine C.)"



- "Projecto Liderazgo hizo que mi caja de habilidades aumente y se fortalezca para crecer personal y profesionalmente me dio habilidades para abogar eficazmente. Y ahora pertenecer y ejercer mi liderazgo en diferentes ocaciones en la comunidad y en la escuela de mis hijos."
- "Project Leadership made my skills box grow and strengthen to grow personally and professionally; it gave me skills to advocate effectively. And now I belong and exercise my leadership on different occasions in the community and at my children's school. (Jacqueline S.)"



New SCDD North Bay Office Manager!

SCDD welcomes a new Regional Office Manager to North Bay! Kenya Martinez has hit the ground running and making big plans to connect with diverse stakeholders. She is being mentored by her tram and the previous NBAY manager, Lisa Hooks, who is now serving as the Sacramento

Regional Office Manager. Kenya has a long history of advocacy, and we are happy to have her join the team! Kenya is meeting with community partners, RAC members, and developing a strategic plan informed by community needs.

Here is a little more about Kenya from her bio:

"To let you know a little more about me, I consider myself a parent/family advocate first and always. I have two adult children with disabilities and a sibling with a disability. I started my journey advocating for my first born and then later on for my adult sibling. The areas I like to focus on in the community are training parents around special education. I am a certified Person-Centered Thinking Trainer, Independent Facilitator and served on the Self-Determination Advisory Committee for my Regional Center for 5 years. During my time off, I enjoy spending time with my husband and family who speak my love languages, which are Sci-Fi, Music, and laughter.

Professionally I have had the honor of working for Disability Rights Education and Defense Fund (DREDF) located in Berkeley as an Educational Advocate, WestED as an Early Intervention Content Specialist, and most recently as an Interagency Manager at Support for Families, located in San Francisco."

CRA/VAS

SCDD AT WORK INSIDE CALIFORNIA DDS STATE-OPERATED FACILITIES

CENSUS As Of July 1, 2024: 220

SCDD commemorates 25 years of interagency collaboration with DDS to serve individuals residing in and transitioning from the DDS California state facilities. SCDD, through the CRA/VAS Program, facilitated the successful closures of the following Developmental Centers - Sonoma, Agnews, Fairview, and Lanterman and Sierra Vista Community Facility. Stockton and Camarillo DC closed prior to 1998. CRA and VAS serves the newly created DDS STAR crisis units. From an institutional population of approximately 5000 individuals in 1998 down to approximately 300 in 2023, SCDD was a key partner in California's deinstitutionalization of individuals with intellectual / developmental disabilities. Thank You current and former CRA and VAS team members. Your work these past 25 years improved thousands of lives.

Program Activity for May and June 2024

Canyon Springs Community Facility and Desert STAR Unit

CRA is monitoring impact of SB 639 on vocational services at CS. CRA attended 8 IPP/special meetings, 4 human rights/behavior meetings; conducted 2 staff trainings on rights, and 2 self-advocacy meetings. VAS filed a WIC Section 4731 complaint for violation of least restrictive environment for one individual awaiting transition. Second level appeal submitted and awaiting response from DDS. VAS attended 27 IPP/specials, 46 transition meetings, and 2 human rights/behavior meetings, attended 1 court hearing, facilitated 2 self advocacy events. Desert STAR unit stopped admitting new individuals on June 30, 2024. Individuals admitted prior to this date will remain at DS until their commitment expires.

Porterville Developmental Center

CRA assisted a client with filing a fair hearing. CRA attended 16 IPP/special meetings; 5 transition meetings, 23 Human Rights and Behavior committee meetings, 4 denial of rights reviews; and 2 self advocacy event. CRA and VAS reviewing the lack of voting rights for people committed to PDC. VAS facilitated increased communication with Public Defenders and their clients. VAS program attended 11 IPP/special team meetings; and 62 transition planning meetings, 2 escort review meetings, facilitated 1 People First event, and 3 court hearings.



Census
Canyon Springs: 32
Desert STAR: 10



Census Porterville DC: 178



Quality Assessment Project (QAP) Report

Eligibility for Family Surveys

Family Surveys collect demographic information on both the individual receiving services ('family member') as well as the person who fills out the survey (the 'respondent') and information on services and supports received.

Child Family Survey (CFS): Mailed to families who have a child family member (ages 17 and under) who lives with the respondent and receives at least one regional center funded service in addition to case management.

Adult Family Surveys (AFS): Mailed to families who have an adult family member (ages 18+) who lives with the respondent and receives at least one regional center funded service in addition to case management.

Family Guardian Survey (FGS): Mailed to families who have an adult family member (ages 18+) who lives in the community (outside the family home) and receives at least one regional center funded service in addition to case management.

Family Survey Cycle

The NCI Family Survey Cycle collection continues with **21,909** completed surveys received in the mail and an additional **6,164** surveys directly entered online by family members, for a total of **28,073** submitted surveys.

The online direct entry (DE) system is available to English speaking family members only, but DDS plans on making the system available in the future in multiple languages. Currently, the print version of each survey is available in 18 different languages. SCDD mails each survey in the language identified by the Regional Center.

The breakdown of these completed surveys by regional center and survey type, as well as by ethnoracial categories can be found in the following pages. Those ethnoracial categories identified in the Population Plan competed by UC Davis include Asian, Black/African American, Hispanic, Other and White.

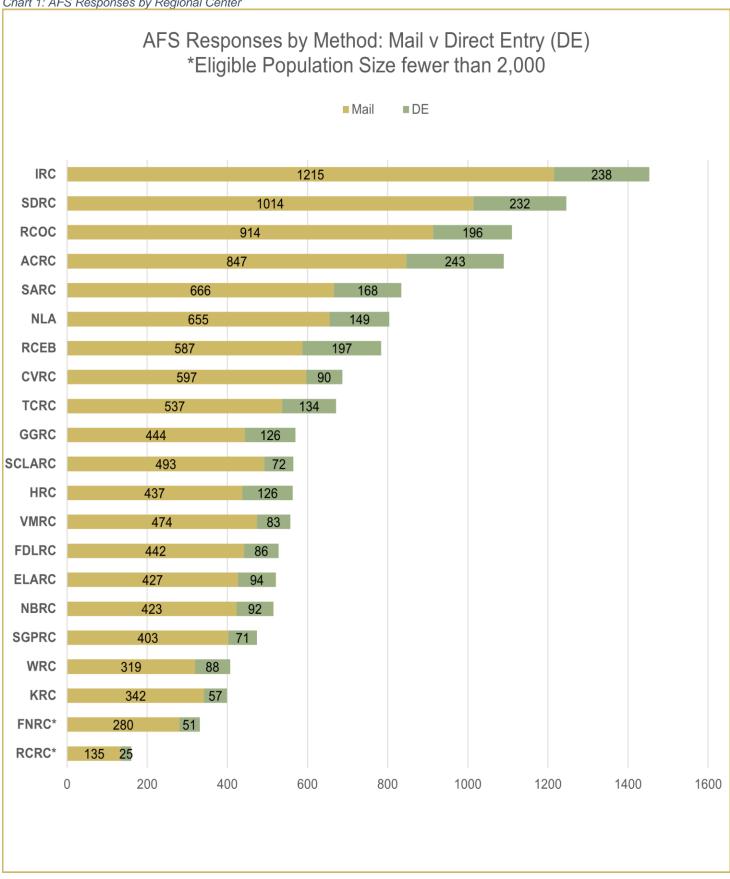


Chart 2: CFS Responses by Regional Center

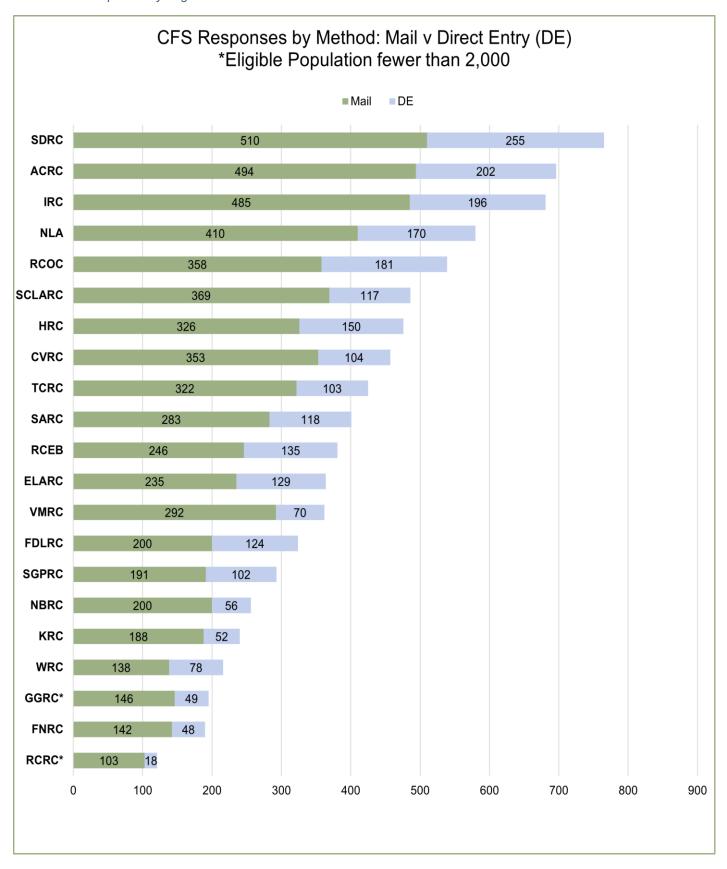


Chart 3: FGS Responses by Regional Center

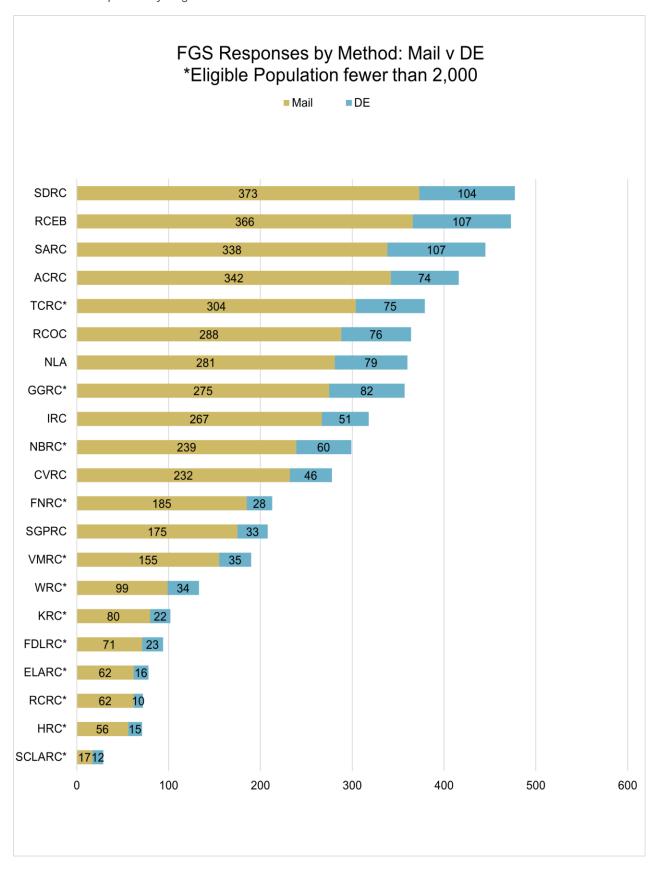


Figure 1: AFS Completed by Race Ethnicity

AFS Completed by Race/Ethnicity

** Regional Centers where the eligible population (N) is less than 2000

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Asian 92 162 176% Black 77 105 136% Hispanic 96 145 151% Other 26 89 342% White 109 283 260% Eastern LA 400 518 Asian 59 106 180% Black 4 6 150% Hispanic 294 338 115% Other 10 17 170% White 33 51 155% Far Northem** 400 332 N = 1712 Asian 13 6 46% Black 9 5 56% Hispanic 63 27 43% Other 19 27 142% White 296 267 90% Frank D. Lanterman 400 526 Asian 55 99 180% Black 29 32 110% Hispanic 199 238 120% Other 9 14 156% White 108 143 132% Golden Gate 400 569 Asian 148 215 145% Black 27 23 85% Hispanic 100 86 86% Other 27 60 222%	W hite	93	222	239%	
Black	East Bay	400	784		
Hispanic 96 145 151% Other 26 89 342% White 109 283 260% Eastern LA 400 518 Asian 59 106 180% Black 4 6 150% Hispanic 294 338 115% Other 10 17 170% White 33 51 155% Far Northem** 400 332 N = 1712 Asian 13 6 46% Hispanic 63 27 43% Other 19 27 142% White 296 267 90% Frank D. Lanterman 400 526 Asian 55 99 180% Black 29 32 110% Hispanic 199 238 120% Other 9 14 156% White 108 143 132% Golden Gate 400 569 Asian 148 215 145% Black 27 23 85% Hispanic 100 86 86% Other 27 60 222%	Asian	92	162	176%	
Other 26 89 342% White 109 283 260% Eastern LA 400 518 Asian 59 106 180% Black 4 6 150% Hispanic 294 338 115% Other 10 17 170% White 33 51 155% Far Northem** 400 332 N = 1712 Asian 13 6 46% Black 9 5 56% Hispanic 63 27 43% Other 19 27 142% White 296 267 90% Frank D. Lanterman 400 526 Asian 55 99 180% Black 29 32 110% Hispanic 199 238 120% Other 9 14 156% White 108 143	Black	77	105	136%	
White 109 283 260% Eastern LA 400 518 A sian 59 106 180% Black 4 6 150% Hispanic 294 338 115% Other 10 17 170% White 33 51 155% Far Northem** 400 332 N = 1712 A sian 13 6 46% Black 9 5 56% Hispanic 63 27 43% Other 19 27 142% White 296 267 90% Frank D. Lanterman 400 526 A sian 55 99 180% Black 29 32 110% Hispanic 199 238 120% Other 9 14 156% White 108 143 132% Golden Gate 400 569 A sian 148 215 145% <td< td=""><td>Hispanic</td><td>96</td><td>145</td><td>151%</td></td<>	Hispanic	96	145	151%	
Eastern LA 400 518 A sian 59 106 180% Black 4 6 150% Hispanic 294 338 115% Other 10 17 170% White 33 51 155% Far Northem** 400 332 N = 1712 A sian 13 6 46% Black 9 5 56% Hispanic 63 27 43% Other 19 27 142% White 296 267 90% Frank D. Lanterman 400 526 A sian 55 99 180% Black 29 32 110% Hispanic 199 238 120% Other 9 14 156% White 108 143 132% Golden Gate 400 569 A sian 148 215 145% Black 27 23 85% Hi	Other	26	89	342%	
Asian 59 106 180% Black 4 6 150% Hispanic 294 338 115% Other 10 17 170% White 33 51 155% Far Northem** 400 332 N = 1712 Asian 13 6 46% Black 9 5 56% Hispanic 63 27 43% Other 19 27 142% White 296 267 90% Frank D. Lanterman 400 526 Asian 55 99 180% Black 29 32 110% Hispanic 199 238 120% Other 9 14 156% White 108 143 132% Golden Gate 400 569 Asian 148 215 145% Black 27 23 85% Hispanic 100 86 86% Other 27 60 222%	White	109	283	260%	
Black 4 6 150% Hispanic 294 338 115% Other 10 17 170% White 33 51 155% Far Northem** 400 332 N = 1712 Asian 13 6 46% Black 9 5 56% Hispanic 63 27 43% Other 19 27 142% White 296 267 90% Frank D. Lanterman 400 526 Asian 55 99 180% Black 29 32 110% Hispanic 199 238 120% Other 9 14 156% White 108 143 132% Golden Gate 400 569 Asian 148 215 145% Black 27 23 85% Hispanic 100 86 86% Other 27 60 222%	Eastern LA	400	518		
Hispanic 294 338 115% Other 10 17 170% White 33 51 155% Far Northem** 400 332 N = 1712 A sian 13 6 46% Black 9 5 56% Hispanic 63 27 43% Other 19 27 142% W hite 296 267 90% Frank D. Lanterman 400 526 A sian 55 99 180% Black 29 32 110% Hispanic 199 238 120% Other 9 14 156% White 108 143 132% Golden Gate 400 569 A sian 148 215 145% Black 27 23 85% Hispanic 100 86 86% Other 27 60 222%	Asian	59	106	180%	
Other 10 17 170% White 33 51 155% Far Northem** 400 332 N = 1712 A sian 13 6 46% Black 9 5 56% Hispanic 63 27 43% Other 19 27 142% White 296 267 90% Frank D. Lanterman 400 526 A sian 55 99 180% Black 29 32 110% Hispanic 199 238 120% Other 9 14 156% White 108 143 132% Golden Gate 400 569 A sian 148 215 145% Black 27 23 85% Hispanic 100 86 86% Other 27 60 222%	Black	4	6	150%	
White 33 51 155% Far Northem** 400 332 N = 1712 A sian 13 6 46% Black 9 5 56% Hispanic 63 27 43% Other 19 27 142% White 296 267 90% Frank D. Lanterman 400 526 A sian 55 99 180% Black 29 32 110% Hispanic 199 238 120% Other 9 14 156% White 108 143 132% Golden Gate 400 569 A sian 148 215 145% Black 27 23 85% Hispanic 100 86 86% Other 27 60 222%	Hispanic	294	338	115%	
Far Northem** 400 332 N = 1712 A sian 13 6 46% Black 9 5 56% Hispanic 63 27 43% Other 19 27 142% W hite 296 267 90% Frank D. Lanterman 400 526 A sian 55 99 180% Black 29 32 110% Hispanic 199 238 120% Other 9 14 156% W hite 108 143 132% Golden Gate 400 569 A sian 148 215 145% Black 27 23 85% Hispanic 100 86 86% Other 27 60 222%	Other	10	17	170%	
Asian 13 6 46% Black 9 5 56% Hispanic 63 27 43% Other 19 27 142% White 296 267 90% Frank D. Lanterman 400 526 Asian 55 99 180% Black 29 32 110% Hispanic 199 238 120% Other 9 14 156% White 108 143 132% Golden Gate 400 569 Asian 148 215 145% Black 27 23 85% Hispanic 100 86 86% Other 27 60 222%	W hite	33	51	155%	
Black 9 5 56% Hispanic 63 27 43% Other 19 27 142% White 296 267 90% Frank D. Lanterman 400 526 Asian 55 99 180% Black 29 32 110% Hispanic 199 238 120% Other 9 14 156% White 108 143 132% Golden Gate 400 569 Asian 148 215 145% Black 27 23 85% Hispanic 100 86 86% Other 27 60 222%	Far Northem**	400	332	N = 1712	
Hispanic 63 27 43% Other 19 27 142% White 296 267 90% Frank D. Lanterman 400 526 Asian 55 99 180% Black 29 32 110% Hispanic 199 238 120% Other 9 14 156% White 108 143 132% Golden Gate 400 569 Asian 148 215 145% Black 27 23 85% Hispanic 100 86 86% Other 27 60 222%	Asian	13	6	46%	
Other 19 27 142% White 296 267 90% Frank D. Lanterman 400 526 Asian 55 99 180% Black 29 32 110% Hispanic 199 238 120% Other 9 14 156% White 108 143 132% Golden Gate 400 569 Asian 148 215 145% Black 27 23 85% Hispanic 100 86 86% Other 27 60 222%	Black	9	5	56%	
White 296 267 90% Frank D. Lanterman 400 526 A sian 55 99 180% Black 29 32 110% Hispanic 199 238 120% Other 9 14 156% White 108 143 132% Golden Gate 400 569 A sian 148 215 145% Black 27 23 85% Hispanic 100 86 86% Other 27 60 222%	Hispanic	63	27	43%	
Frank D. Lanterman 400 526 Asian 55 99 180% Black 29 32 110% Hispanic 199 238 120% Other 9 14 156% W hite 108 143 132% Golden Gate 400 569 A sian 148 215 145% Black 27 23 85% Hispanic 100 86 86% Other 27 60 222%	Other	19	27	142%	
Asian 55 99 180% Black 29 32 110% Hispanic 199 238 120% Other 9 14 156% White 108 143 132% Golden Gate 400 569 Asian 148 215 145% Black 27 23 85% Hispanic 100 86 86% Other 27 60 222%	White	296	267	90%	
Asian 55 99 180% Black 29 32 110% Hispanic 199 238 120% Other 9 14 156% White 108 143 132% Golden Gate 400 569 Asian 148 215 145% Black 27 23 85% Hispanic 100 86 86% Other 27 60 222%	Frank D. Lanterman	400	526		
Hispanic 199 238 120% Other 9 14 156% W hite 108 143 132% Golden Gate 400 569 A sian 148 215 145% Black 27 23 85% Hispanic 100 86 86% Other 27 60 222%					
Hispanic 199 238 120% Other 9 14 156% W hite 108 143 132% Golden Gate 400 569 A sian 148 215 145% Black 27 23 85% Hispanic 100 86 86% Other 27 60 222%	Black	29			
White 108 143 132% Golden Gate 400 569 A sian 148 215 145% Black 27 23 85% Hispanic 100 86 86% Other 27 60 222%	Hispanic	199	238	120%	
Golden Gate 400 569 A sian 148 215 145% Black 27 23 85% Hispanic 100 86 86% Other 27 60 222%			14	156%	
Asian 148 215 145% Black 27 23 85% Hispanic 100 86 86% Other 27 60 222%	W hite	108	143	132%	
Asian 148 215 145% Black 27 23 85% Hispanic 100 86 86% Other 27 60 222%					
Black 27 23 85% Hispanic 100 86 86% Other 27 60 222%					
Hispanic 100 86 86% Other 27 60 222%					
Other 27 60 222%					
vv nite 98 185 1 89%	White	98		189%	

Figure 2: AFS Completed by Race/Ethnicity (Continued)

Harbor	400	555	
Asian	61		157%
Black	44		77%
Hispanic	178		99%
Other	37		200%
White	80		219%
Inland	400	1442	
Asian	19	82	432%
Black	50	161	322%
Hispanic	211	608	288%
Other	20	85	425%
White	100	506	506%
Kern	400	401	
Asian	14	21	150%
Black	35	27	77%
Hispanic	217	199	92%
Other	19	20	105%
White	115	134	117%
North Bay	400	517	
Asian	35	41	117%
Black	42	39	93%
Hispanic	118	117	99%
Other	35	56	160%
White	170	264	155%
North LA County	400	712	
Asian	30		253%
Black	42		136%
Hispanic	195		163%
Other	11		445%
White	122		175%
Orange County	400	1088	
Asian	78		290%
Black	7		257%
Hispanic	145		213%
Other	44		239%
White	126		341%
Redwood Coast**	400		N= 954
Asian	7		86%
Black	12		17%
Hispanic	67		24%
Other	26		35%
White	288	125	43%

Figure 3: AFS Completed by Race/Ethnicity (Continued)

	000	
400	823	
		111%
		145%
		304%
	275	286%
400	1240	
38		345%
27	54	200%
185	452	244%
28	122	436%
122	481	394%
400	470	
60	72	120%
21	21	100%
244	245	100%
21	30	143%
54	102	189%
400	563	
		150%
	_	153%
		136%
		113%
		233%
		200 70
		221%
		129%
	_	135%
		269%
		187%
		157%
		114%
		186%
		175%
		95%
		77%
		100%
85	115	135%
Goal	Complete	
8400	14090	
977	1873	192%
746	1009	135%
3590		137%
		234%
	108 9 160 27 96 400 38 27 185 28 122 400 60 21 244 21 54 400 4 90 292 8 6 400 19 7 185 16 173 400 42 35 167 22 134 400 20 107 155 33 85 Goal 8400 977 746	108

Figure 4: CFS Completed by Race/Ethnicity

CFS Completed by Race/Ethnicity

** Regional Centers where the eligible population (N) is less than 2,000

regional centers where the engine population (N) is less than 2,000				
	Goal	Complete	% Goal	
Alta California	400	693		
Asian	53	93	175%	
Black	42	35	83%	
Hispanic	92	153	166%	
Other	69	128	186%	
W hite	144	284	197%	
Central Valley	400	454		
Asian	23	34	148%	
Black	15	11	73%	
Hispanic	253	290	115%	
Other	49	54	110%	
W hite	60	65	108%	
East Bay	400	368		
Asian	99	78	79%	
Black	50	25	50%	
Hispanic	137	93	68%	
Other	44		220%	
W hite	70	75	107%	
Eastern LA	400	363		
Asian	52		144%	
Black	5		80%	
Hispanic	296	223	75%	
Other	25		144%	
White	22	25	114%	
Far Northem	400	190		
Asian	9		22%	
Black	7		14%	
Hispanic	81	43	53%	
Other	28		64%	
White	275		46%	
Frank D. Lanterman	400			
Asian	52		117%	
Black	24		50%	
Hispanic	210		60%	
Other	8		138%	
White	106		106%	
Golden Gate	400	190		
Asian	117		64%	
Black	17		29%	
Hispanic	143		35%	
Other	49		35%	
White	74		58%	
TTING	74	43	0010	

Figure 5: CFS Completed Race Ethnicity (continued)

Harbor	400	476	
Asian	49		143%
Black	36		83%
Hispanic	203		115%
Other	69		116%
White	43		147%
Inland	400	672	
Asian	18		222%
Black	32		122%
Hispanic	181		166%
Other	103		156%
White	66		200%
Kern	400	238	
Asian	16	5	31%
Black	30	11	37%
Hispanic	244	149	61%
Other	25	18	72%
White	85	55	65%
North Bay	400	256	
Asian	26	14	54%
Black	28	16	57%
Hispanic	165	99	60%
Other	74	51	69%
White	107	76	71%
North LA County	400	581	
Asian	28	44	157%
Black	39	28	72%
Hispanic	224	318	142%
Other	17	47	276%
White	92		157%
Orange County	400	530	
Asian	85		165%
Black	7	3	43%
Hispanic	144		118%
Other	83		119%
White	81		146%
Redwood Coast**	400		N= 1088
Asian	7		14%
Black	7		0%
Hispanic	100		26%
Other	48		33%
White	238	78	33%

Figure 6: CFS Completed by Race/Ethnicity (Continued)

Con Androso	400	440	
San Andreas	400	413	
Asian	103		112%
Black	4		100%
Hispanic	187		90%
Other	54		104%
White	52		133%
San Diego	400	760	
Asian	35		271%
Black	16		163%
Hispanic	186		167%
Other	83		192%
White	80	170	213%
San Gabriel/Pomona	400	293	
Asian	71	73	103%
Black	14	7	50%
Hispanic	269	143	53%
Other	16	45	281%
White	30	25	83%
South Central LA	400	482	
Asian	2		100%
Black	57		104%
Hispanic	317		128%
Other	20		60%
White	4		75%
Tri-Counties	400	425	1076
Asian	12		133%
Black	4		75%
Hispanic	225		107%
Other	32		109%
White	127		102%
Valley Mountain	400	364	1000/
Asian	45		100%
Black	31		52%
Hispanic	202		97%
Other	42		95%
White	80		84%
Westside	400	215	
Asian	17		82%
Black	94		52%
Hispanic	169		38%
Other	45	43	96%
White	75	44	59%
	Goal	Complete	% Goal
Report Totals	8400	8406	100%
Asian	919		119%
Black	559		69%
Hispanic	4028	3803	
Other	983		124%
Other			
White	1911	1904	100%

Figure 7: FGS Completed by Race/Ethnicity

FGS Completed by Race/Ethnicity

** Regional Centers where the eligible population (N) is less than 2,000

** Regional Centers where the eligible population (N) is less than 2,000						
	Goal	Complete	% Goal			
Alta California	400	411				
Asian	18	16	89%			
Black	55	24	44%			
Hispanic	34	17	50%			
Other	20	29	145%			
White	273	325	119%			
Central Valley	400	274				
Asian	14	4	29%			
Black	37	14	14%			
Hispanic	129	54	42%			
Other	11	8	73%			
White	209	194	93%			
East Bay	400	464				
Asian	44	45	102%			
Black	82	45	55%			
Hispanic	38	29	76%			
Other	14	34	243%			
W hite	222	311	140%			
Eastern LA**	400	75	N= 797			
Asian	49	8	16%			
Black	14	2	14%			
Hispanic	194	20	10%			
Other	6	3	50%			
W hite	137	42	31%			
Far Northem**	400	207	N=1665			
Asian	4	2	50%			
Black	10	5	50%			
Hispanic	18	9	50%			
Other	18	10	56%			
White	350	181	52%			
Frank D. Lanterman**	400	90	N=721			
Asian	60	13	22%			
Black	41	8	20%			
Hispanic	86	9	10%			
Other	7	4	57%			
W hite	206	56	27%			
Golden Gate**	400	339	N=1683			
Asian	54	27	50%			
Black	46	16	35%			
Hispanic	36	17	47%			
Other	18	21	117%			
W hite	246	258	105%			

Continued on next page

Figure 8: FGS Completed by Race/Ethnicity (continued)

Harbor**	400		N=997
Asian	48		19%
Black	64		13%
Hispanic	83		10%
Other	21		38%
White	184		21%
Inland	400	306	
Asian	10	12	120%
Black	51		41%
Hispanic	93	44	47%
Other	13	8	62%
White	233	221	95%
Kern**	400	94	N=1115
Asian	12	4	33%
Black	46	2	4%
Hispanic	96		10%
Other	15	4	27%
White	231	74	32%
North Bay**	400	295	N= 1675
Asian	14		50%
Black	41	18	44%
Hispanic	32		31%
Other	16	13	81%
White	297		83%
North LA County	400	354	
Asian	20		105%
Black	44	13	30%
Hispanic	73		51%
Other	6		133%
White	257		107%
Orange County	400	323	
Asian	40		108%
Black	11		73%
Hispanic	56		2%
Other	30		90%
White	263		93%
Redwood Coast**	400		N=653
Asian	400		0%
Black	6		0%
Hispanic	15	1	
Other	24		13%
			19%
White	351	6/	1970

Continued on next page

Figure 9: FGS Completed by Race/Ethnicity (continued)

San Andreas	400	433	
A sian	40		85%
Black	18		56%
Hispanic	80		58%
Other	18		156%
White	244	315	129%
San Diego	400	466	
A sian	18		83%
Black	35		51%
Hispanic	78	45	58%
Other	15	26	173%
White	254	362	143%
San Gabriel/Pomona	400	208	
Asian	32	22	69%
Black	40	17	43%
Hispanic	122	28	23%
Other	16		56%
White	190	132	69%
South Central LA**	400		N=549
Asian	11		9%
Black	200		6%
Hispanic	124		4%
Other	15		13%
White	50		14%
Tri-Counties**	400		N=1939
Asian	13		92%
Black	12		58%
Hispanic	74		31%
Other	12		192%
White	289		107%
Valley Mountain**	400		N= 1649
Asian	20		50%
Black	42		12%
Hispanic	62		32%
Other	14		57%
White	262		55%
Westside**	400		N=848
Asian	19		37%
Black	100		21%
Hispanic	68		12%
Other	22		27%
White	191		45%
vvriite	191	60	1370
	Goal	·	% Goal
Report Totals	8400	5197	
Asian	544		57%
Black	995	274	28%
Hispanic	1591		28%
Other	331	282	85%
White	4939	3888	79%

About National Core Indicators

National Core Indicators[™](NCI) strives to provide states with valid and reliable tools to help improve system performance and better serve people with intellectual and developmental disabilities and their families.

Through a contract with Department of Developmental Services (DDS), State Council on Developmental Disabilities (SCDD), using the NCI Survey tools, collects quantitative data on consumer satisfaction, provision of services, and personal outcomes. Data collection is completed through face to face interviews with consumers as well as mail-in surveys from families.

This data collection effort will enable DDS to evaluate the quality and performance of California's developmental disability service delivery system and among all the 21 regional centers over time.

For results of past surveys go to: https://www.dds.ca.gov/rc/nci/reports/

To view the DDS NCI Dashboard go to:

https://www.dds.ca.gov/rc/nci/

For more information about the NCI go to:

https://www.nationalcoreindicators.org/

Scan QR code below to go to QA Project Webpage scdd.ca.gov/qap





QAC Regional Center Assignments

QAC: Vacant
Support Staff: Sarah Wirrig
Far Northern
North Bay
Redwood Coast

Ron Usac Support Staff: Valerie Buell East Bay San Andreas

George Lewis
Support Staff: Vacant
Alta California
Central Valley
Valley Mountain

Lia Cervantes-Lerma • Brianna Reynoso • Jenny Villanueva

Support Staff: Austin Murphy and Marina Bchtikian

East Los Angeles
Frank D. Lanterman
Harbor
North Los Angeles
San Gabriel Pomona
South Central Los Angeles
Westside

Angel Wiley
Priscilla Huang, SSA
SSA: Vacant
Staff Support: Vacant
Golden Gate
Orange County
San Diego

Matoya Terrell
Support Staff: Jose Valle
Inland
Kern
Tri-Counties

JULY 16, 2024

AGENDA ITEM 9. INFORMATION ITEM

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Statewide Self-Advocacy Network (SSAN) Report

The Statewide Self-Advocacy Network (SSAN) is a project of the Council. Members will hear updates from Councilmember Alex Reyes on recent activities.

Attachment

June 2024 SSAN Update Report

July 16, 2024 AGENDA ITEM 8. INFORMATION ITEM



STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Summary of June 2024 Statewide Self-Advocate Network (SSAN) Meeting

Recent Activity: The Statewide Self-Advocacy Network (SSAN) held a hybrid meeting on June 6, 2024, in Sacramento and over Zoom.

Focus of Meeting:

The June 2024 SSAN meeting was held at the Holiday Inn Sacramento Downtown and on Zoom. The meeting began with members sharing tips on how they prepare for emergencies.

The meeting featured updates from SCDD and updates on the development of the Master Plan on Developmental Services.

The SCDD Updates featured SCDD staffing changes, key federal and state budget updates effecting the agency, the status of SCDD sponsored and supported legislation, updates on the SCDD Self-Determination Program and updates on Supported Decision-Making Technical Assistance Program (SDM-TAP). The proposed federal budget for the October 2024 – September 2025 includes level funding for State Councils on Developmental Disabilities, meaning that the federal part of SCDD's budget and work will stay the same. The proposed state budget includes budget authority for a Support Service Assistant (SSA) for SCDD staff with Intellectual and Developmental Disabilities (I/DD), permanent staff for the Self-Determination Program Orientation and Training, permanent staff for the Statewide Self-Determination Advisory Committee (SSDAC), and to keep distributing go-kits.

Enrollment in the Self-Determination Program (SDP) continues to increase. As of March 31, 2024, there are 4,242 regional center clients enrolled in the program. Unfortunately, there continues to be an under-representation (less people enrolled) of minorities within the program, which was highlighted in a recent Los Angeles Times news article.

Members expressed concern about the decline of in-person self-advocacy participation in many regions and that the effort needed to participate in self-determination was making it hard for regional center clients to participate and understand the program.

July 16, 2024 AGENDA ITEM 8. INFORMATION ITEM



STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Summary of June 2024 Statewide Self-Advocate Network (SSAN) Meeting

SSAN members Nicole Patterson, Kecia Weller, and Lisa Cooley provided an update on the development of the Master Plan on Developmental Services. Development of the Master Plan on Developmental Services is still in the early stages and is a collaborative effort between representatives from different agencies, organizations, and advocates. The goal is to have a comprehensive plan drafted by March 2025. The committee developing the Master Plan is taking input from focus groups and round table discussions, comments during meetings, and comments submitted to DSMasterPlan@chhs.ca.gov to guide the development process. Please visit http://www.chhs.ca.gov/home/master-plan-for-developmental-services/ to learn more about the development process.

Members shared that the Master Plan should include the need for grief counseling, access to affordable and accessible housing, training for medical professionals, emergency responders, mental health professionals, and law enforcement and helping people with I/DD cope with loneliness. The committee developing the master plan are looking for people to participate in future workgroups. Members interested in joining a workgroup related to the master plan are encouraged to inform Nicole.

2022 - 2024 SSAN Leadership:

Chair: Charles Nutt, North State Regional Representative

Vice-Chair: Nicole Patterson, DDS Representative

Secretary: Rebecca Donabed, Sequoia Regional Representative

Actions Taken:

Approved the Minutes from the February 2024 SSAN Meeting

The next SSAN Meeting will be held over Zoom in September. Be on the lookout for more details and visit the SSAN Page on the SCDD website for more information.

JULY 16, 2024

AGENDA ITEM 10. INFORMATION ITEM

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Updates on the Lanterman Act

Will Leiner and Viviana Haun with Disability Rights California (DRC) were invited to present on changes to the Lanterman Act included in this year's budget. They have been actively involved in the negotiations and drafting of proposals concerning virtual individual program plans (IPPs) and social recreation.

Handout(s)

May be additional handout(s) day of meeting.

JULY 16, 2024

AGENDA ITEM 11.

ACTION ITEM

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Cycle 47 Grant Proposals

One of the many ways the Council carries out the work of its State Plan is by awarding program development grants, also known as Cycle Grants, to community-based organizations to research, develop and/or implement innovative programs and promising or best practices throughout the state and its local communities.

In March, the Council approved the RFP project descriptions for Cycle 47 Program development Grants. RFPs were released on March 27th with a submission due date of May 22nd. This deadline provided time for the scoring team to read the proposals before they met on June 14th. The State Plan Committee then met on June 27th and were presented with the scoring team's findings and subsequent recommendations. At this meeting Councilmembers will be presented with the State Plan Committee's Grant Cycle 47 funding recommendations and asked to take action to approve the recommended projects for funding and direct the Executive Director to administer the contract process.

Attachment

Grant Descriptions
Cycle 47 PDF Grants PPT

Action Recommended

Approve the State Plan Committee's Cycle 47 Grant funding recommendations and direct the Executive Director to administer the contract process.

Proposal Number: App-24-169

Recommended Funding: \$220,500.00

Project Area: Self-Advocacy (Isolation/Loneliness)

Number of People to be Served: 600 (300 SA, 100 FA & 200 others)

Proposal Summary:

As a tangible way to move from a position of social isolation into meaningful belonging within a community of choice, the proposed project will provide people with intellectual/developmental disabilities (PwI/DD; self-advocates [SA]) person-centered support and social and emotional skills development, helping participants to overcome anxiety and self-limiting beliefs about community participation. Individualized coaching and online and in-person meetings will provide opportunities to learn valuable skills, explore interest areas, and connect.

Key Activities:

- **1.** Engage in recruitment of participants from underserved populations (e.g. Southeast Asians, Native Americans, Latinos, African-Americans, Slavic/Russians, the Deaf community, etc.)
- 2. Participants will participate in four (4) online meeting groups across three interest tracks: a) Health and Wellbeing; b) Art and Creativity; and, c) Social Recreation and Hobbies (up to 600 PwI/DD in 24 virtual meetings)
- **3.** Participants may attend up to four (4) in-person regional group meetings across each of their chosen interest areas/tracks, each of which will showcase community/regional groups and opportunities in the identified areas of interest (84 in-person meetings)
- **4.** Participants will also receive coaching for individualized needs and will help develop an action plan for community participation and integration, using person-centered tools and motivational interviewing

- **5.** Direct service providers (DSP) and family members (FA) of socially isolated adults will have access to one of three webinars, to learn both practical community engagement skills and insights to provide emotional support and encouragement
- **6.** Provide opportunities for peer mentors/coaches to engage/work with participants

Outcomes:

The project will establish evidence for training within a social and emotional learning skills program that 'bridges' people out of loneliness. At least 24 PwI/DD will participate in a leadership role for in-person meetings and individualized coaching will be provided to at least 50 PwI/DD. Through activities, participants will be exposed to a minimum of 30 community-based engagement opportunities. This project will support one (1) promising practice and create four (4) best practices, in addition to training 200 professionals (DSP's). The agency expects to gather data/evidence to establish the program as a best practice and to prove that a coached 'interest track' engagement group is a best practice model to reinforce pro-social community engagement.

Agency Description:

This agency (based in Redding, California) has been providing services to DDS (CA Dept. of Developmental Services) clients and families for 26 years, servicing five (5) different regional centers with training, technical assistance, and grant-funded projects. The agency currently provides supported and independent living services and coordinated family supports, all of which are community-based and consistently require collaboration with natural support and generic resources. It works with a range of service recipients from many different cultural backgrounds, in rural and remote regions, and provides training and resources in English and Spanish.

Proposal Number: App-24-201

Recommended Funding: \$62,245.00

Project Area: Self-Advocacy (Plain Language)

Number of People to be Served: 40 Self-Advocates

Proposal Summary:

The Inclusive Communication Project will build upon evidence-based best practice(s) and/or, best practices, emphasizing plain language as a universal design strategy for communication and understanding and educating government agencies, private businesses, and service providers about the importance of plain language. It will provide 'how-to' guides (in English and Spanish) to put these standards into practice. A course will be provided to train PwI/DD and family members to translate difficult-to-understand, inaccessible content into usable, plain language information. Those skills can be used to explore employment opportunities in local communities, including microenterprise startups. The final plain language course will be offered to the larger community, with an online resource toolkit containing employment marketing materials and outreach ideas for families and service providers across the state (and beyond). A final report about methods utilized, lessons learned, and recommendations for future use will also be provided.

Key Activities:

- Create a plain language toolkit with targeted resources to educate government agencies, private businesses and service providers about the importance and benefits of using inclusive plain language for public-facing content
- 2. Create a How-To Guide (in English and Spanish) to share tips, best practices, tools and examples of how to convert work products into plain language, with emphasis on the importance of providing culturally competent materials

- 3. Provide training and resources for individuals with I/DD and their family members on converting difficult-to-understand information into plain language. Course modules will cover plain language basics as well as how to use existing tools to assist with translation.
- 4. Educate people with I/DD and their family members on how to apply the skills they have developed to gain access to competitive, integrated employment opportunities.
- 5. Develop an Employment Marketing Toolkit with resources to assist individuals with I/DD and their family members with creating resumes and developing marketing materials and a plan for reaching potential employers/customers.
- 6. Provide a comprehensive report outlining the methods used, lessons learned, and recommendations for project replication

Outcomes:

This project will support systems change by providing information and resources to assist public agencies, businesses and service providers with creating plain language materials and putting plain language policies and procedures in place. Forty (40) Individuals with I/DD and/or their family members will gain the resources and skills to translate difficult-to-understand information into plain language and to use these skills to achieve competitive, integrated employment. At least 100 businesses, government agencies, or service providers will increase their plain language skills by using the How-To Guide and at least 10 of these organizations will make changes to their policies or procedures related to plain language public-facing communication.

Agency Description:

This agency is an organization at the forefront of research and innovation to improve public health and promote health, well-being, and health equity in communities around the world. It offers administrative and contract management systems designed for successful program staffing, fiscal

accountability, and timely completion of deliverables. A third of the leadership team of one of its programs (actually tasked with implementing the project) includes PwI/DD, including the project lead. This program prioritizes serving underserved communities and marginalized populations.



CYCLE 47 PDF GRANTS REQUEST FOR PROPOSAL (RFP)

Feb. - March '24

- 2/15: SPC met to determine recommendations for Grant Cycle 47 process, areas of emphasis, and timeline
- 3/12: SPC reviewed scoring criteria & project descriptions

May '24

- 5/10: Proposals Deadline
- 5/26: Administrative Review Completed

March '24

- 3/19: Council reviews and votes on SPC Cycle 47 recommendations
- 3/22: Cycle 47 RFP Released

June '24

• 6/4: DEAP review completed

• 6/14: Scoring Panel meets

• 6/27: SPC Reviews Scoring Panel

Recommendations

Oct. '24

• 10/1: Cycle 47 Projects begin

July '24

• 7/16: State Council votes on SPC Recommendations for Cycle 47 Recipients

• 7/16 - 7/26: Protest period

• 7/29: Award notification

Grant Cycle 47 Focus Areas & Allocated Funds

The Council has a total of \$300,000 available to fund Cycle 47 PDG projects in three (3) proposed areas:

- Self-Advocacy (Isolation/Loneliness)
- Self-Advocacy (Plain Language)
- Tribal Health

Initial Reviews

•SCDD received a total of 11 grant proposals

Administrative Review: 7 proposals failed

Total amount of requested funds:\$1,407,537

Proposal Scoring Criteria

- Knowledge & Experience
- Project Description
- State Plan
- Target Population
- Diversity/Disparities
- Implementation Plan
- Project Activities

- Project Timeline
- Deliverable(s)/Output(s)
- Outcomes
- Impact
- Evaluation & Reporting
- Innovation & Creativity
- Budget

Scoring Team reviewed 4 Proposals

Scoring Team Review

- 2 Self-Advocacy (Isolation/Loneliness)
- 1 Self-Advocacy (Plain Language)
- 1 Tribal Health

Scoring Team is recommending 2 project proposals

- 1 Self-Advocacy (Isolation/Loneliness)
- 1 Self-Advocacy (Plain Language)

Total amount of recommended funds: \$282,745

SCORING TEAM RECOMMENDATIONS

Cycle 47

SELF-ADVOCACY

ISOLATION LONELINESS

Recommended Funding:

\$220,500

Number of People Served:

600 (300 SA, 100 FA and 200 Others)

Proposal APP #24-169

Proposal Highlights:

Engage SA statewide in virtual meetings across 3 interest tracks: Health and Well-being; Art and Creativity; and Social Recreation and Hobbies

Hold in-person regional meetings to showcase community/regional groups and opportunities for social engagement

Provide person-centered support and emotional skills development to SA participants, and hold webinars to teach family members and Direct Service Providers skills to provide support and encouragement to socially isolated individuals

#APP-24-169 Project Description

This project will create a replicable program to reduce social isolation by providing opportunities for self-advocates (SA) to explore their interests, develop social and emotional skills, and connect with community/regional groups in their areas of interest. Participants will develop an action plan for community engagement and family members and service providers will learn community engagement skills and gain insights to provide support and encouragement to self-advocates

SELF-ADVOCACY

PLAIN LANGUAGE

Recommended Funding:

\$62,245

Number of People Served:

40 SA and 100 government agencies, businesses, and/or service providers

Proposal

APP

#24-201

Proposal Highlights:

Create plain language toolkit resources to educate government agencies, businesses and service providers about the importance of creating plain language content and implementing plain language policies and procedures

Give SA and FA training and resources to translate information into plain language, with skills to create micro-enterprises and/or gain access to competitive, integrated employment opportunities

Final report with methodology, lessons learned, and recommendations for project replication

APP #24-201 Project Description

This project will provide self-advocates and family members with skills and resources to translate complex content into plain language, and to develop resumes and/or marketing materials to get competitive integrated employment (CIE). Government agencies, businesses and service providers will be educated about the importance of creating plain language content and will have access to resources to implement plain language policies in their organization(s).



QUESTIONS

PROPOSED MOTION

"Approve the State Plan Committee's Cycle 47
Grant funding recommendations and direct the
Executive Director to administer the contract
process."

SPC REQUEST

The State Plan Committee (SPC) is requesting additional funding from the Council to relaunch a Cycle 47 RFP with a focus on Tribal Health.

JULY 16, 2024

AGENDA ITEM 12. INFORMATION ITEM

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Person-Centered Thinking

Self-advocate Evan Barnwell and Councilmember Viviana Barnwell will present on person-centered thinking in planning and services.

In the past 30 years, the support systems for older adults and people with disabilities have changed dramatically. In that time, long-term services and supports have generally moved to embrace person-centered values which are dedicated to the idea that individuals should have the power to define and pursue their own vision for a good life. However, many systems still struggle to put person-centered principles into practice and deliver on these commitments.

People who facilitate person-centered planning play a key-role in ensuring a person-centered system. For the planning process to be truly person-centered, it is critical that staff who facilitate person-centered planning possess the skills to keep the focus on the person, cultivate connections, maximize choice and control, communicate clearly, and make sure the plan is implemented according to the person's wishes.

What is person-centered thinking, planning, and practice?

- Person-centered thinking focuses language, values, and actions toward respecting the views of the person and their loved ones. It emphasizes quality of life, well-being, and informed choice.
- Person-centered planning is directed by the person with helpers they choose. It is a way to learn about the choices and interests that make up a good life and identify the supports (paid and unpaid) needed to achieve it.
- Person-centered practices are present when people have the full benefit of community living and supports are designed to assist people as they work toward their desired life goals.

Source: National Center on Advancing Person- Centered Practices and Systems (NCAPPS) is an initiative from the Administration for Community Living (ACL) and the Centers for Medicare & Medicaid Services (CMS)

Attachments

Person-Centered Planning: Choosing the Approach that Works for the Person Person-Centered Planning: Five skill areas facilitators should have to best support person-centered planning (Plain Language Version)

Handout(s)

May be additional handout(s) day of meeting.



Person-Centered Planning: Choosing the Approach that Works for the Person

January 2024

By Valerie J. Bradley



Introduction

Despite consensus regarding the content and conduct of person-centered plans (such as the personcentered planning requirements in the Home and Community-Based Services Final Rule), there has been less promising practice guidance on how to tailor the duration and extent of the planning process to the needs and wishes of the person. To be truly person-centered, the content and extent of the planning process should be tailored to the person's unique life circumstances. The intent of this resource is to reinforce the importance of aligning person-centered planning approaches with the wishes and needs of the person for whom the plan is being developed, rather than adopting a one-size-fits-all approach.

History and Background

The concept of person-centered planning was first conceived in the 1980s by a small number of people working in the U.S. and Canada including John O'Brien, Connie Lyle O'Brien, Beth Mount, Jack Pearpoint, Marsha Forest, and Michael Smull. It was initially developed to facilitate the movement of people with disabilities out of remote institutions into lives in the community (Inclusive Solutions, n.d.). From the start, person-centered planning was built on the values of inclusion and choice and tied paid and unpaid supports to goals and aspirations. Person-centered plans were originally designed as an alternative to plans based on the medical model of disability that led to an emphasis on deficits and to service

decisions made by an array of clinical professionals. Historically, such deficit-based plans were developed mainly for the convenience of the provider, not to support the person's goals.

Rules developed by the Centers for Medicare and Medicaid Services now require service plans to follow person-centered principles that put each person's goals, preferences and needs at the center of the planning conversation. Although person-centered planning was developed as an alternative by leaders in the disability field, it is increasingly used to organize services and supports for a wide spectrum of people needing support across a range of settings. For instance, Kim and Park (2017) highlighted the power of person-centered planning for people with dementia and Lines et al. (2015) described the positive effect of person-centered planning principles in patient-centered care. When planning puts the person at the center of the conversation, research has shown that costs are reduced and, more importantly, that lives improve (Sanderson, et al., 2006).

What Self-Advocates Say

- Tia Nelis: ". . . the person with a disability is in charge of their plan. Everyone should listen to what the person with the disability wants; they choose who supports them and who comes to the meeting;"
- Liz Weintraub: "A person-centered plan is about what the person (me) wants. . . it's also important to LISTEN to the person when doing a person-centered plan, no matter if that's hard to do;"
- Nicole LeBlanc: "I think it . . . means that having control of your life and (be) empower(ed) to tell what you want in our life;"
- James Meadours: "One that is truly inclusive of Wishes, Hopes, Dreams of people with disabilities . . . staff that think outside the box"



Person-centered planning is not one defined process, but a range or continuum of processes all underpinned by the same values base and goal – to provide supports necessary to assist people to gain agency in their lives. It should be thought of as an umbrella concept that encompasses different purposes, content, and frequency depending on the needs of the person and regulatory requirements. The overarching aim of planning for any purpose should be to reflect the person's wishes and aspirations.

Operationalizing Person-Centered Planning



Until the Home and Community-Based Services (HCBS) Final Rule in 2014, federal guidance from the Centers for Medicare and Medicaid Services regarding planning for HCBS waiver recipients was limited to specific waiver assurances including ensuring that they address assessed needs and health and welfare risks, include the person's

goals and preferences, are updated when needs change, afford choice among services and providers, and include the opportunity to self-direct.

Since the release of the HCBS Final Rule, CMS has required that all people receiving HCBS services and supports must have a person-centered plan that meets criteria including that the plan be written in plain language, include people chosen by the person, is driven by the person, and reflects cultural considerations (see list of requirements in the Appendix).

However, the HCBS Final Rule does not include specific guidance related to the extensiveness of the plan and its alignment with a person's circumstances and need/preferences for support. While it is true that states providing HCBS waiver services are obligated to conduct person-centered plans for people receiving services and supports in ways that align with the process and plan standards set forth in the HCBS Final Rule, there is little guidance regarding how to tailor the wide-ranging aspects and components of person-centered planning to the immediate context of the person for whom the plan is being developed.

In this section, we outline different contexts and approaches to person-centered planning and highlight the importance of specifying the purpose and extensiveness of planning activities based on a person's circumstances and preferences.

Range of Planning Formats

Significant Life Event Planning

Over the past several decades since person-centered planning was first introduced, several formats have been developed to provide tools and a structure for the process such as PATH, MAPS, Personal Futures Planning, Essential Lifestyle Planning, and Charting the LifeCourse. Each of these approaches anticipates the need to respond to a significant life event such as transition from school to adulthood, retirement, movement into employment or supported housing, and other major life changes (see NCAPPS, Person-



Centered Thinking, Planning, and Practice: A National Environmental Scan of Foundational Resources and Approaches). Each entails a comprehensive process that involves the person with a disability and others in their life in a wide-ranging conversation about goals, potential obstacles, community supports, growth milestones and anticipated changes over time.

This form of planning requires supporting people to explore their options, understanding their long-term aspirations, linking paid and non-paid supports to those aspirations, and thinking about the trajectory of their lives. This type of planning does not always get into the details of how services are to be delivered on a day-to-day basis but instead tackles bigger issues like where and with whom to live or work, and how to make the transition happen smoothly. It also can be done by the person or a member of their circle of support, through private facilitators, or public support coordinators.

Ongoing and/or Periodic Person-Centered Service Planning



A more routine form of person-centered planning for people receiving HCBS occurs at least yearly as required by CMS. Some states may require more frequent personcentered plans depending on the population. Periodic person-centered service planning is convened by a case manager or coordinator, or public human services agency to review the allocation of public resources, assess progress, determine whether the service and support mix continues to meet the person's needs, initiate

or update a specific service, or respond to a change in the person's life. This service planning process should have continuity with prior services planned and delivered and should, to be person-centered, be driven by the person receiving services, with acknowledgment for service system dynamics and specific provider experiences and availability. Person-centered service planning should reflect the ongoing incorporation of learning by all members of the person's circle. The anticipated duration of existing service plan goals and objectives should also inform the frequency of plan updates.

The format, content, and frequency of this form of planning is usually dictated by regulatory or policy guidance from a public agency (see Croft, et al., 2020). Person-centered service plans cover the provision of paid supports but should also take into consideration the availability of unpaid supports and personal strengths. Yearly person-centered service plans should also provide any specific services and supports linked to a person's long-term goals (e.g., those identified in a plan developed in response to significant life events as described in the section above).

Aligning the Plan with the Individual Circumstances



Because of the comprehensive nature of significant life event planning and the amount of time, attention and introspection required, plans for significant life events by definition should not occur on a set schedule (e.g., every year) but rather at important junctures in the person's life. This form of planning is at one end of a continuum, and routine yearly person-centered service planning is at the other end. To ensure plans

are person-centered, the trick is to determine when some of the more in-depth planning elements should be infused into a plan and under what circumstances. People's lives rarely shift on a set schedule determined by a human service agency, necessitating flexibility and fluidity in both the planning and oversight processes to ensure that the system's demands don't undermine the person-centeredness of the planning.



Determining the point on that continuum should depend on the immediacy of needs, changes in the person's situation and/or aspirations, and the nature of the planning process favored by the person. For instance, if a person is receiving only a few hours of support a week to meet their needs, and if their goals and support needs are unlikely to change over time, their plan should be brief and to the point.

One of the important requirements for the plan is that the person knows how to signal that their needs have changed. If the change is equivalent to a major life transition, the person and their circle of support including the service coordinator may agree that a significant life event planning approach may be necessary. The bottom line is that the content and duration of the planning process should be personcentered in that it takes into account the unique context surrounding the person. The challenge going forward is to ensure that the person-centered plan neither overwhelms nor underserves the beneficiary of the plan.

Other Important Considerations

There are some key additional considerations to ensure that the person-centered planning process results in outcomes that are consistent with the person's goal and needs. The first is monitoring to ensure that the planning process is appropriate to the scope and complexity of needs and that the supports in the plan in fact align with the person's needs. Further, are the supports as envisioned available? Can they be implemented as anticipated? Will they lead to desired results?



Second, regardless of the planning process employed, many people cannot "lead" their plan unless they are supported to lead. This means that the person-centered planning process in many instances should start before the actual plan is discussed to make sure that the person understands their role, the issues they want discussed, any boundaries they want to uphold, and what their hoped-for outcomes are.

Third, aspirations in the person-centered plan should not just be exhortations but should be linked to supports and services that are likely to result in success. Those who support people during the planning process should be wary of making commitments that have very little chance of being honored given the support and service mix proposed.

Promising Practices

The person-centered planning process must include people chosen by the person. Therefore, plans should document exactly who is part of the person's inner circle and the roles they play in the person's life.

In order to "right size" the planning process based on individual needs and preferences, there are some promising practices that case managers and other supporters might consider. The goal would be to allow the person to influence how extensive the process will be. Further, the process should relieve the person from having to "tell their story" over and over.

Some potential approaches include:

Pre-populating information from the initial assessment into the person-centered plan template in order to avoid going over the same ground during each planning session.



- Reviewing the current planning and eligibility process to determine those threshold questions that are important to determine eligibility for services, the level of services and supports the person needs, and the content of the Person-Centered Support Plan. These questions may cover a range of domains such as activities of daily living, memory and cognition, and challenging behavior. As part of the foundational questions, people should be offered the opportunity to self-direct and to seek employment.
- If people are interested and willing to provide more personal information, developing a set of questions including such issues as volunteering, training, preferences for support for activities of daily living (e.g., bathing, dressing, eating), interest in becoming a self-advocate, and how to help your caregiver.
- Creating a module for people who choose to share their "personal story."
- Working with the person in anticipation of the planning process in order to ensure that they understand what information will be shared and whether they want to volunteer to share any additional personal information.

This tiered approach should generate the information necessary to create a person-centered plan as well as a framework that allows people to pick and choose the information they choose to share.

Conclusion

There are several steps that public managers, self-advocates, advocates, and others can take to ensure that the plan fits the needs of the person:

- State regulations and guidelines should emphasize the elements that should be part of any plan but also lay out the options for duration, frequency, and content, etc. along the continuum of planning formats.
- Plan facilitator training should provide a discussion of the criteria to be applied in each circumstance prior to arriving at a planning format including consultation with the person.
- Feedback from people who use plans including and especially people with disabilities and other support needs – should be gathered to understand what is working and what is not working in the planning process and identify areas for improving the relevance and appropriateness of plans.
- Plan review processes should include assurances that plans are in fact tailored to the particular context of the person and that the plan supports realistic expectations and desired outcomes.
- People should be supported to lead their own plans with access to information, assistance, and guidance before the planning event.



This discussion is premised on the assumption that there is no one-size-fits-all approach to personcentered planning. It is also critical to regard all planning as perpetually moving forward in time and being updated and revised. No new plan should occur in isolation from prior efforts nor should elements of time limit the revising of goals or changing strategies per the person's wishes. Though all plans should be governed by the values of choice, inclusion, and empowerment, they should reflect the specific circumstances of the person. If the plan is no more than a check-in, then the process – and the plan – can be brief. At the other end of the spectrum, if the person has or is about to experience a significant life event (a new stage of life, a traumatic event, a complex health challenge), then the process should be as comprehensive as necessary to address the person's needs and priorities. Further, the extent and content of the plan should reflect the desires of the person. It should consider the person's comfort level with repeated self-disclosures and tolerance with the duration of the planning event.

Appendix

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About NCAPPS

The National Center on Advancing Person-Centered Practices and Systems (NCAPPS) is an initiative from the Administration for Community Living (ACL) and the Centers for Medicare & Medicaid Services (CMS) to help States, Tribes, and Territories implement person-centered practices. It is administered by the Human Services Research Institute (HSRI).

You can find us at https://ncapps.acl.gov

This blog is the work of Valerie J. Bradley and does not necessarily represent the views of NCAPPS, HSRI, ACL, or CMS.

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Person-Centered Planning



Five skill areas facilitators should have to best support person-centered planning

Plain Language Version | January 2021



Person-centered planning is a way to learn about a person's idea of a good life. It focuses on the supports (paid and unpaid) they need. It is directed by the person. They might get support from someone known as a "facilitator." The facilitator could be a **Case Manager**, a **Support Coordinator**, or a **Peer Specialist**. Or it could be **someone else** who can help create the plan.

What Skills Should Facilitators Have?

Facilitators need certain skills and abilities to make person-centered planning work. These skills are also called "competencies." Here, we describe five skill areas that facilitators should have. These skills support a good person-centered planning process.

Who Is This Document For?

This document is for people who want to learn about the five skill areas that facilitators should have. This is good information for people who use person-centered planning—and for their families. It will help them know what to expect from their facilitator (the person helping).

1. Strengths-Based, Culturally Informed, Whole Person-Focused

What does this mean? Person-centered planning recognizes that people grow and change. It focuses on helping the person live their idea of a good life. All the planning steps should focus on the person—and not just their diagnosis or disability. The planning should also focus on the person's unique culture and identity.

Facilitators should:

- Be aware of their own culture and identity. Understand that the person's values and culture may differ from the service system's values and culture.
- Learn about the person's culture and language. Respect the person's values and beliefs, customs, and rituals.
- Use helpful tools to find out about the person's goals and their idea of a good life. Use tools that support people to choose their own services.
- Hold high expectations for the person's quality of life in areas that the person values.
- See the person's strengths and interests beyond their disability or diagnosis. Not assume what a person can or cannot do based on their disability.



2. Cultivating Connections Inside the System and Out

What does this mean? Planning includes all different kinds of supports. Supports might be from providers or from friends or family. All the planning actions should connect people to community activities and build relationships with people who matter to the person.

Facilitators should:

- Understand the systems and supports a person may choose. They may include things like:
 - health care
 - social services
 - recreation
 - housing and employment supports
 - faith-based organizations and events
 - resources provided by cultural groups
 - food pantries and clothing donations
- Understand the needs of different groups of people. For example, older adults or people with disabilities.
- Help the person connect to community activities. Help the person develop relationships that matter most to them.
- Involve family caregivers and/or other supporters in the planning process.
- Understand that a meaningful life in the community is a human right and not something people have to earn.



3. Rights, Choice, and Control

What does this mean? Planning activities are based on respect. The person is expected and supported to make decisions about their own life.

People are supported to find their voice in creating their plan. People learn about their rights.

Facilitators should:

- Understand that all people have the right and ability to participate in the planning process.
- Understand the concepts of "dignity of risk." This means that people have a right to fail. People can learn from their mistakes.
- Tell people about their rights in the service system and in the community. Know about the history and achievements of disability and aging advocacy groups.
- Support people to speak up for themselves during the planning process. Help when things are tense or when providers or supporters are disagreeing with the person.
- Practice supported decision-making. This means helping the person to make and communicate decisions about their life.
- Know how to tell if the person is being abused, neglected, or mistreated. Know how to report this.

4. Partnership, Teamwork, Facilitation, and Coordination

What does this mean? Planning meetings are held in a respectful, professional way. The person can bring in more people and supporters if they want. All people on the person's team are helped to be a part of the planning process.

Facilitators should:

- Respect how the person identifies. Understand the difference between person-first vs. identity-first language.
- Respect the person's input about planning meetings. This includes things like: Who is invited? Where is it held? When it is held? Who leads the meeting?
- Hold the meetings in a respectful, professional manner. This covers things like:
 - start the meeting on time
 - keep down disruptions
 - give the person full attention
 - check with the person to be sure they understand
 - ask the person if they have questions
- Listen to all the team members during the meeting. Make sure the person's voice is a priority.
- Make sure the team gets a copy of the plan and can make changes. Help them make changes as needed.
- Help the team work through differences and conflicts.
- Maintain a focus on the person's life goals and outcomes.

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5. Person-Centered Plan Documentation, Implementation, and Monitoring

What does this mean? The person-centered plan is made together and put in writing. The plan is a "living document" that can be updated as needed. There is follow-up and monitoring of the plan.

Facilitators should:

- Include the person's strengths, interests, and talents in their plan. This is also done when carrying out the plan.
- Write the plan using the person's preferred name, language, and identity.
- Use language that is clear and accessible to describe the goals. Use the person's own words when they can.
- Write down the services and supports (paid and unpaid) in the plan.
- Find out from the person and their supporters how the plan is going.
- Make sure that everyone is sticking to the plan. Make sure that services are happening as the person wants them to.

Final Thoughts

It's important that people know what to expect from their services. This resource is meant to explain the skills that facilitators need to help with person-centered planning. But there is no "right" way to do person-centered planning. It needs to be flexible. Every person is different, and every person-centered plan is different.

About NCAPPS

The National Center on Advancing Person-Centered Practices and Systems (NCAPPS) is an initiative from the Administration for Community Living and the Centers for Medicare & Medicaid Services to help States, Tribes, and Territories to implement person-centered practices. It is administered by the Human Services Research Institute (HSRI) and overseen by a group of national experts with lived experience (people with personal, first-hand experience of using long-term services and supports).

NCAPPS partners with a host of national associations and subject matter experts to deliver knowledgeable and targeted technical assistance.

You can find us at https://ncapps.acl.gov

This document is a plain language version of *Five Competency Domains for Staff Who Facilitate Person-Centered Planning*, available at https://ncapps.acl.gov. All NCAPPS resources are publicly available for use in the administration and improvement of supports for older adults and people with long-term service and support needs. All uses should acknowledge NCAPPS and the developers of this content. Permission is required if the material is to be modified in any way or used in broad distribution.

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AGENDA ITEM 13. INFORMATION ITEM

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

History of People First

Councilmember Rosie Ryan will present on the history of People First.

People First of California was established to empower individuals with developmental disabilities. Founded as a self-advocacy organization, its origins trace back to Oregon in 1974. The name "People First" signifies the importance of recognizing individuals as people before their disabilities. In California, the movement has grown significantly, with multiple chapters across the state. Their mission is to train, inform, and support peers to speak up for themselves, understand their rights, make decisions, and stand united. The organization envisions a world where all people with disabilities gain empowerment through unity and mutual respect.

Handout(s)

May be additional handout(s) day of meeting.

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AGENDA ITEM 14. INFORMATION ITEM

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

Next Meeting Date and Adjournment

The Council's next meeting date is scheduled to be in person on September 24, 2024.