



STATE COUNCIL ON DEVELOPMENTAL DISABILITIES
BAY AREA REGIONAL ADVISORY COMMITTEE (RAC) MEETING & COMMUNITY OUTREACH

NOTICE & AGENDA



Date Wednesday, September 28, 2016



Time 7:00pm – 9:00pm



Location Marin Office of Education, 111 Las Gallinas Ave, San Rafael, CA 94110
Phone: 415.472.4110

Can't travel to the meeting? Toll Free dial-in option: 1-800-839-9416 PIN: 3424727

This Regional Advisory Committee Agenda is posted on:

<http://www.scdd.ca.gov/bayarea.htm>

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510.286.0439 or by email Valerie.Buell@scdd.ca.gov

Requests must be received by 5pm on September 21st, 2016

Please refrain from wearing scented products at this meeting





7:00p Call to Order
Introductions / Establishment of Quorum

Rauch
Nicholau



7:10p Approval of the meeting minutes of 2/24/16 and 6/29/16

Rauch



7:15p Public Comment

An invitation to provide the public an opportunity to comment and/or present information to the Committee on **any matter that is not on the agenda**. Each public member is afforded up to 3 minutes to speak. Written requests will be considered first. The Committee will provide a public comment period not to exceed 5 minutes total for all public comments prior to action on any agenda item.



7:25p Overview & Following Discussion: State Council's Legislative Platform

Nicholau

Based on the draft 2017 Legislative Platform, please provide feedback and specific changes in statutes SCDD should pursue next year in the following areas: Self-Determination, Employment, Equity, Transportation, Healthcare, Education, Housing, Self-Advocacy, Community Participation, Transition to Adult Life, Rates for Services, Health & Safety, and Quality of Services & Supports



8:15p Update & Discussion: Home & Community Based Services (HCBS) Final Rules

Nicholau

Latest news re. CA's waiver, follow up conversation from June's RAC



8:30p Reports

Rauch

- Chair Report
- Regional Center Reports
- County DD Council Reports
- People First Report



8:45p Manager's Report

Nicholau

- First 100-day report
- Self-Determination update
- Membership and Elections update for Regional Advisory Committee & State Council





8:50p Other Announcements & Agenda Items for Future Meetings

An opportunity of members of the community to bring up ideas, needs, issues and concerns



9:00p Meeting Adjourned

Rauch





**State Council on Developmental Disabilities
Bay Area Regional Advisory Committee Meeting
February 24, 2016 Minutes DRAFT**

Location: Golden Gate Regional Center, 3130 La Selva Dr., San Mateo

Committee Members Present: Nicole Adler (SA), Sherrie Auren (SA), Sascha Bittner (SA), Francisco Garcia (FA), Kate Rauch (FA), Francis Lau (FA)

Committee Members Absent: Donna Adkins (FA), John Kalb (FA), Karen Vanderwoert (SA), Dianne Millner (FA), Pam Perls (FA)

Guests: Jim Shorter (GGRC), Cheryl White (Cedars of Marin), Vera Lanz (Marin Ventures), Debora Adler (FA), Lisa Rosene (GGRC), Shawnte Ayalew (FA), Shirley Pots, Beverly Buell

Staff: Gabriel Rogin and Valerie Buell

7:08p Call to order and introductions

7:10p Motion to approve the minutes from the Committee Meeting on September 30, 2015; Moved by Sherrie Auren and seconded by Francisco Garcia. Approved (all Ayes)

7:11p Community Outreach:

Shawnte Ayalew brought up her concerns about her daughter not getting services. There was discussion about the difficulties parents go through communicating with regional centers and doing more outreach to the community to help them understand what is available and what to ask for, as well as looking into providing a Q&A and a clear definition of acronyms.

7:20p Jim Shorter gave a report on the Golden Gate Regional Center Caseload Ratios.

7:40p There was discussion on the presentation.

7:49p Cheryl White from Cedars of Marin gave a Presentation on Intellectual/Developmental Disabilities and Dementia

8:19p Discussion on the presentation and the role the State Council has in bringing all the different agencies together to communicate with each other on the issues and needs of people in the community.

Down Syndrome Connection may be doing some type of Forum. Gabriel Rogin will get information on the date/time of the Forum.



8:26p Discussion 2016 Mini Grant Focus Areas. Papers were passed out to vote on top 3 priorities from the state plan to decide what to recommend to the state council to be the focus of this Mini Grant.

8:37p Kate Rauch announced Contra Costa County is finally moving ahead with an employment program, county employees for people with developmental disabilities. This has not been approved by the board of supervisors yet. It is moving into consideration.

8:41p Gabriel Rogin announced that he has been acting as the Chief Deputy Director of the State Council. He will continue in that position and the Regional Manager position in the Bay Area Office will be posted soon and someone will be hired soon. This will be the last meeting Gabriel attends as the Regional Manager of the Bay Area Office.

8:44p Valerie Buell read out loud the results of the paper ballots.

Results of the paper ballots and emailed ballot

Employment 0 votes

Housing 3 Votes (2 first priority, 1 second priority)

Health and Safety 3 Votes (1 first priority, 1 second priority, and 1 third priority)

Early Intervention & Education 5 votes (1 first priority, 1 second priority, and 3 third priority)

Formal and Informal Community Supports 4 votes (1 first priority, 2 second priority, and 1 third priority)

Self-Advocacy 4 votes (2 first priority, 2 second priority)

8:45p Kate Rauch lead the discussion on the paper ballets and how to decide what the priority is based on how varied the priorities were in the vote totals. Nicole Adler spoke about how important Health and Safety is for the community and how safety is on the minds of people with disabilities right now, and there was detailed discussion on what Formal and Informal Community Supports means to the different members of the committee.

Early Intervention and Education got the most number of votes (5). Formal and Informal Community Supports and Self Advocacy tied for the second highest number of total votes (4 each).

After discussion about both Formal and Informal Community Supports and Early Intervention and Education it was decided that Formal and Informal Community Supports is First Priority and Early Intervention and Education is Second Priority.

9:15p Gabriel Rogin announced that the Central Coast Office and Silicon Valley Office are proposed to be merged. This will not affect the Bay Area Office. The only loss to the Bay Area Office is the loss of the position formerly held by Denis Craig. There are no other changes planned for the Bay Area Office.

9:16p Meeting Adjourned

*notes available on request



**State Council on Developmental Disabilities
Bay Area Regional Advisory Committee Meeting
June 29, 2016 Minutes DRAFT**

Location: Regional Center of the East Bay, 1320 Willow Pass Road, Concord

Committee Members Present: Sascha Bittner (SA), Francisco Garcia (FA), Pam Perls (FA)

State Council Member Present: Francis Lau (FA)

Committee Members Absent: Donna Adkins (FA), Nicole Adler (SA), Sherrie Auren (SA), Dianne Millner (FA), Kate Rauch (FA),

Guests: Morena Grimaldi (FA), Angela Gattis (Care Parent Network), Linda Stevens (FA), Irene Litherland (FA& DD Council), Geneva Ziaoure (FA & Manos/PUAC), Lisa Kleinbub (RCEB), Ronke Sodipo (RCEB), Jim Burton (ED RCEB), Sara Desumala (People First SF), Patrick MacKay (SA), Jerry Grace (People First NAC), Eric Zigman (GGRC), Will Sanford (Futures Explored), Donna Feingold (Adaptive Learning Center), Bill Pelter (Ability Now Bay Area), Sandi Soliday (Alameda County DD Council), Karen Lingenfelter (Mt. Diablo USD), Danita Stevens (FA), Kym Luqman (Harambee), Jennifer Torai (Stanford Health Care)

Staff: Sheraden Nicholau, Ron Usac, and Valerie Buell

7:05p Call to order and introductions

No vote on approving the minutes from February due to lack of quorum.

7:13p Community Outreach had no comments from those present.

7:14p Power Point Presentation/Discussion and request for feedback by Sheraden Nicholau: Home and Community Based Services (HCBS) Final Rules. *See power point print out for presentation attached to hard copy of agenda. Notes below are the Q/A

Sheraden: The State Council wants feedback from this RAC on:

Based on the info we have right now...

- Where are we with HCBS?
- What kind of outreach is needed?
- What are some concerns?
- What questions aren't answered?

Questions included:

- Why it is happening?
- Is the Final Transition plan ready? Do we have 30 days to comment unless they make substantive changes (and then we have 30 more days)? What's going to happen when this



is a mandate but there's no money that comes with it? Are we allowed as a committee to comment rather than as individuals on the plan?

- Are we just stating or defining the places that are not home and community based? Are we saying we don't want nursing homes and hospitals used? Are they trying to change all this in general? Is this going to be more defined?
- Will there be enough time in the process?

Comments included:

- We are moving away from people living long-term in large institutional settings like hospitals or developmental centers or nursing homes.
- The target is for a least-restrictive living situation, and obviously we would want that for seniors and everyone else
- As of March 2019 the state will need to be in compliance.
- The Federal Government has given guidelines and mandates of what they expect to see in our waiver application.
- At times, people with dual-diagnosis, often end up staying in an inappropriate medical facility because their support team may not be able to find other options.
- Many group homes in the state have closed down due to funding.
- There is enough time in the process to give consults, feedback, and recommendations to the Council and to the state in general. CA's waiver has not been approved, and full compliance is due in March 2019.
- DDS has had a committee meeting about this. See DDS's website for updates and Fact Sheets

Sascha Bittner asked that the committee be informed about any future updates on HCBS and the Final Rule.

7:49p Sheraden Nicholau gave an Overview and held a discussion on Disparity and Equity Questions facing our system.

*See print out for NCI Results From People Across California in 2014-2015, Total Annual Expenditures and Authorized Services by Diagnosis – Summary GGRC Fiscal Year 2014-2015, and RCEB Purchase of Services Expenditure and Demographic Data attached to hard copy of agenda. Notes below are the Q/A.

Questions Included

- Is it possible to focus on the entry points?
- How can we better support the parents?

Comments Included

- Access to information is essential. It takes a long time for parents to find their way (navigating through regional center services).
- We need a culturally competent mentoring program. Making sure that programs are not just focusing on language, but focusing on cultural competency.



- Ensuring that services and resources are, whenever possible, coming from the population, rather than outsiders bringing information in.
- We need emotional support, physical access in relation to geographical location of supports and services.
- Use of social media, and targeting social media based on the demographic we are trying to reach.
- More accessible parenting classes for different demographics that may be underserved in this area.
- Leadership and advocacy education within the groups that we are looking to target; ‘training the trainers’
- Families are afraid to speak because they don’t know what will happen, but when they feel they are in a place that can change their lives, they will speak up.
- Language and cultural appropriateness of resources, and making sure these are in the hands of not only our system, but partners like medical facilities, pediatricians, and schools.
- A centralized roadmap that is accessible to different groups/demographics.
- Best practices like; what works in this region, what has a track record of being successful in terms about reaching and empowering our groups, and duplicating those best practices.
- Making sure that we use plain language, getting away from acronyms whenever possible when it comes to our communication, whether in print or person to person.
- Taking different work schedules and lifestyles into account.
- Congreso Familiar is an example of helping families know how to advocate and to get to the right person at the right moment.
- Families are afraid to take a day off work to go get resources for their children, so they need help with that. They are driving for over an hour to get the information and they are willing to learn, but it is too risky taking time off work.
- RCEB has set up a Diversity and Equity Committee. One of the things that we noticed in our community; there were a number of Asian language populations that didn’t have any purchase of service for adults. There needs to be support to develop startup funding to support those communities.
- More money needs to be given to the regional centers to support that big program because they are the funnel to everyone else.
- There just seems to be all this information for when kids are younger, and then all of a sudden, at 22, ‘everything is dead’.
- Regional centers should pay these case workers more money so they don’t use this job as a stepping stone. There are a lot of turnovers with caseworkers.
- GGRC has had a lot of conversations about disparity and in San Francisco, there are 162 languages spoken. We have done some things to make lists available in Spanish and Chinese, on the website we are going to try to add more Lanterman services with translation.
- We have to meet communities when they have time to be able to respond. This is an important issue and the language is the tip of the iceberg. It is cultural sensitivity that is going to be important.



8:16p Sheraden lead a discussion on Regional Advisory Committee needs for the year ahead.

*See letter dated May 19, 2015 on the structure of the Regional Advisory Committee, The Frequently Asked Questions on policy questions about the Regional Advisory Committees, the memo on The Procedures for Regional Advisory Committee input and/or recommendations to the State Council, The Issue Advisory/Request form, and The 2016-2017 Schedule of Council Meetings attached to hard copy of agenda. Notes below are the discussion.

Sandi Soliday: An RSVP is not needed for the meeting in Oakland on November 30, 2016.

Comments Included

- The meeting in Marin County is hard to get to.
- The Bay Area Office will look at that and see if there are more accessible locations in Marin County.
- The Bay Area Office can send out the meeting schedule to anyone who requests it, and it is posted on our website.

8:22p The Membership Committee for the State Council will be meeting in July, if you are in between terms and maybe haven't submitted your application yet and would like to, now is the time to do so.

8:31p Sheraden Nicholau gave a Staff Report:

- State Council Regional Offices are working with Headquarters on the next 5-year state plan. We will be sharing the summary report on the outcomes of the last 5 year plan with this committee and with our partners.
- The State Council has been working on supporting several pieces of legislation. One is SB 1072 the school bus bill that Senator Mendoza has been working on.
- If there are chapters of People First that would like to write a letter or create a card for the family of Paul Lee, the State Council staff would be happy to facilitate making sure that that gets to the family through the State Council.
- We finished the Grant Cycle 39. It will be wrapped up very quickly so that the chosen project can get started this summer.

8:38p Jim Burton gave the Regional Center Report for RCEB:

- RCEB has just moved offices and is hosting tonight's meeting in the new building. ABX 21 is happening.
- In special session, legislation provided significant salary increases for direct care staff, service providers, and regional centers.
- Every rate for every program will need to be changed.
- The Governor included funding for 200 new case managers at regional centers statewide.
- Closure of Sonoma Developmental Center is actively underway.
-

Eric Zigman gave the Regional Center Report for GGRC:



- The legislature feels like they gave us a big rate increase but we're going to have to reeducate them, to thank them for the stabilization, but to move forward with building the community system.
- The median rates were put into place in 2008-2009 as a way to control costs. It was effective in saving money, but it was damaging in both current providers being able to pay their staff and in damaging in attracting folks to build new services or expand the services they had.
- We will be partnering and continuing to partner with the State Council on the Self-Determination Advisory Committee. We are waiting for the Federal Government to approve another Self-Determination waiver.

Sheraden Nicholau mentioned that Self-Determination will be on the next agenda with the possibility of one of the Pilot Project members speaking to the committee as well. Sascha suggested that the November meeting may be a better meeting to have that presentation.

8:46p Jerry Grace gave the People First Report:

- We held a People First conference in Sacramento and I went as a representative of Bay Area People First.
- This Saturday, July 2nd will be the next Northern Alameda chapter meeting for People First from 12:30 to 2:00 PM at the Cesar Chavez branch of the Oakland Public Library at 3301 East 12th Street, Suite 271. It is near the Fruitvale BART station. Anyone can come to our meeting. Parents and family members cannot be members of People First, but they can be supporters.

8:51p Sandi Soliday gave the DD Council report:

- Next meeting of the Alameda County DD Council is Wednesday July 13th at 9:00 AM. This is the annual planning meeting. Please come and contribute your ideas.
- We also have an East Bay Employment Taskforce meeting August 5th at the Public Health offices in San Leandro.

8:52p Public Comments:

Will Sanford:

- An event was held for Contra Costa County for emergency response teams. They believe that one of the left out areas is this community. In a major anthrax emergency, "How do you dispense medications broadly?"
- An all-day training was done to help address that question.

8:56p Meeting Adjourned

*Documents referenced were in the RAC packets and in the handouts at the meeting for guests. They can also be found on the website www.scdd.ca.gov/bayarea.htm



**Agenda said Board Member Items, but it is corrected here in the notes as Committee Member Items as we are no longer Area Board 5.

***Notes (and Documents) Available Upon Request



LEGISLATIVE and Public Policy Platform



Proposed for 2017



About the Council

The federal Developmental Disabilities

Assistance and Bill of Rights Act of 2000

Establishes State Councils on Developmental Disabilities in each of the 56 states and territories to promote self-determination, independence, productivity, integration, and inclusion in all aspects of community life for people with intellectual and developmental disabilities (I/DD) and their families. The Lanterman Act establishes the California State Council on Developmental Disabilities (Council) to fulfill those obligations through advocacy, capacity building, and systems change.

To that end, the Council develops and implements goals, objectives, and strategies designed to improve and enhance the availability and quality of services and supports.

The Council is comprised of 31 members

appointed by the Governor, including

individuals with disabilities and their families, and representatives from Disability Rights California, the University Centers for Excellence in Developmental Disabilities, and state agencies.

In addition to the Council's Sacramento headquarters, regional offices support individuals with I/DD and their families through activities such as advocacy training, monitoring, and public information. The Council strives to ensure that appropriate laws, regulations, and policies pertaining to the rights of individuals are observed and protected.

This document conveys the Council's position on major policy issues that affect individuals with I/DD and their families.



Promise of the Lanterman Act

The Lanterman Act promises to honor the needs and choices of individuals with I/DD by establishing an array of quality services throughout the state. Services shall support people to live integrated, productive lives in their home communities, in the least restrictive environment. Access to needed services and supports must not be undermined through categorical service elimination, service caps, means testing, or family cost participation fees and other financial barriers.

California must not impose artificial limitations or reductions in community-based services and supports that would compromise the health and safety of persons with I/DD.



SELF-DETERMINATION

Individuals with I/DD (intellectual and developmental disabilities) and their families must be given the option to control their service dollars and their services through Self-Determination. The person with I/DD is in charge. With the support of those they choose and trust, people with I/DD and their families are best suited to understand their own unique needs, develop their own life goals, and construct those services and supports most appropriate to reach their full potential. The process begins with a Person Centered Plan (PCP). Self-Determination gives individuals the tools and the basic human right to pursue life, liberty, and happiness in the ways that they choose.



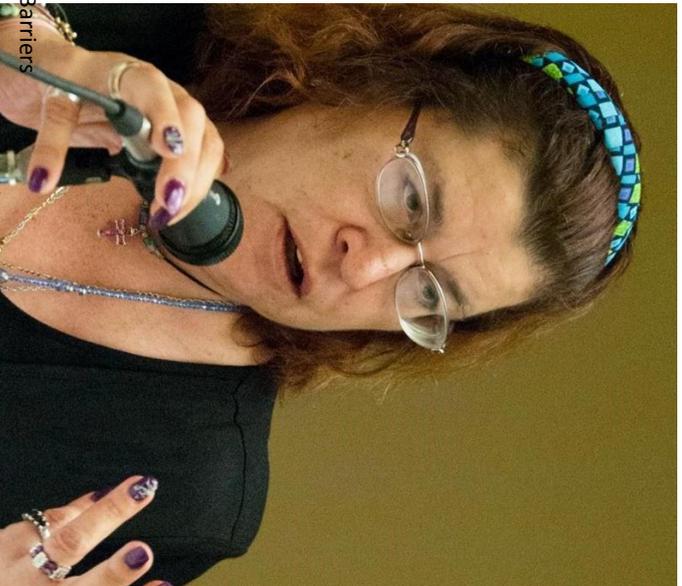
EMPLOYMENT

Competitive Integrated Employment (CIE) gives people an opportunity to contribute and be valued. It gives them a chance to build relationships with co-workers, be a part of their communities, and contribute to their local economies. It reduces poverty and reliance on state support and leads to greater self-sufficiency. The Council supports the initiatives of the Workforce Investment Opportunity Act (WIOA), Home and Community-Based Services (HCBS), and California's Employment First law.

CIE is the priority outcome for working age individuals with I/DD, regardless of the severity of their disability. Transition planning should begin as early as possible. Policies and practices must set expectations for employment, promote collaboration between state agencies, and remove barriers to CIE through access to information, benefits counseling, job training, postsecondary education, and appropriate provider rates that incentivize quality employment outcomes.

EQUITY

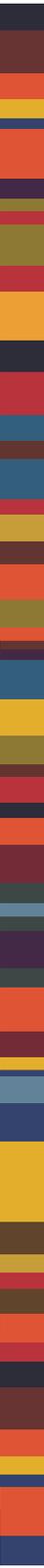
Disparities in services can result in severe health, economic, and quality of life consequences. Accordingly, services and supports must be distributed equitably so that individual needs are met in a culturally appropriate and linguistically competent manner, regardless of race, ethnicity, or income.



Barriers

TRANSPORTATION

Access to transportation is essential to the education, employment, and inclusion of individuals with disabilities. Individuals with I/DD must be a part of transportation planning and policymaking to assure their needs and perspectives are heard and addressed. Mobility training must be a standard program among transportation providers to increase the use of available transportation and reduce reliance on more costly segregated systems. Barriers between geographic areas and transportation systems must be broken down so people with I/DD can travel as easily as anyone else.



HEALTH CARE

California has an obligation to assure that individuals with I/DD have continuity of quality care, a full continuum of health care and wellness services, and access to plain language information and supports to make informed decisions about their health care options.

California has an obligation to support timely, efficient health and dental care for individuals with I/DD. This includes informed consent, prevention of overmedication and an adequate network of health professionals. It also includes people with multiple health care needs, those who require routine preventative care, mental and/or behavioral health treatment, dental care, durable medical equipment, and those with reproductive health issues.

Service system complexities must be reduced. Individuals must be reimbursed for insurance co-pays, co-insurance, and deductibles when their health insurance covers therapies that are on their Individual Program Plans (IPPs).



EDUCATION

Schools must implement the Individuals with Disabilities Education Act (IDEA), as well as state laws and regulations, to provide students with I/DD with free appropriate public education (FAPE) and prepare them for post-secondary education, employment, and living in their communities. Students with disabilities will be educated alongside their non-disabled peers in the least restrictive environment. Transition planning should be considered part of the IPP process. School districts and other educational agencies need to be held accountable for implementing the letter and the intent of all state and federal laws, and parents must have equal participation in the Individual Education Plan (IEP) process, including the ability to give informed consent. Transparency is paramount. The Council opposes all forms of seclusion and restraint techniques.

HOUSING

People with I/DD must be involved in policy and decision making related to housing. Community integrated living options for individuals with I/DD must be increased and enhanced through access to housing subsidy programs and community education and integration to reduce discrimination. Permanent, affordable, accessible, and sustained housing options must be continually developed to meet both current and future needs.

SELF-ADVOCACY

Individuals with I/DD must be supported to exert maximum control over their lives. They must be provided the opportunity and support to assume their rightful leadership in the service system and society, including voting and other civic responsibilities. Self-advocates must have access to training, plain language materials, and policy making opportunities.

COMMUNITY PARTICIPATION

Individuals with I/DD must have access to and be supported to participate in their communities, with their non-disabled peers, through opportunities such as education, employment, recreation, organizational affiliations, spiritual development, and civic responsibilities.

TRANSITION TO ADULT LIFE

All services, including education, rehabilitation, and regional center services, must support students to transition to competitive integrated employment or post-secondary educational opportunities that will lead to meaningful employment. Transition services must be considered at the earliest possible opportunity. Adults with I/DD must have access to meaningful activities of their choice with the appropriate services and supports.



RATES FOR SERVICES

The state must restore rates to adequately support the availability of quality services for people with all disabilities in all the systems that serve them. A planned and systematic approach to rate adjustments must prioritize and incentivize services and supports that best promote self-determination, independence, employment, and inclusion in all aspects of community life.

HEALTH AND SAFETY

All people have a right to be safe. People with I/DD need emergency preparedness training. Individuals with I/DD experience a much greater rate of victimization and a far lower rate of prosecution for crimes against them. The same level of due process protections must be provided to all people. Individuals with I/DD should be trained in personal safety, how to protect themselves against becoming victims of crime, and how their participation in identification and prosecution can make a difference. In addition, too many interactions between law enforcement and people with I/DD end in avoidable tragedy. Law enforcement personnel, first responders, and the judicial system must be trained in how to work with people with I/DD who they interact with during the course of their duties, including those who are victims of crimes.



QUALITY OF SERVICES AND SUPPORTS

The State of California must ensure that funding is used to achieve positive outcomes for individuals with I/DD and their families. An adequate safety net must be in place to address medical, psychiatric, behavioral, residential, staffing, equipment, or other needs when those services or supports fail, are interrupted, are not available, or additional services and supports are necessary for urgent or immediate need. The state must streamline burdensome and duplicative regulations and processes that do not lead to positive outcomes for people with I/DD and their families. Quality assessment and oversight must be provided by the state; it must measure what matters, be administered in a culturally competent manner, and the results made public and used to improve the system of services and supports.



California State Council Regional Offices

North Coast (707) 463-4700

Counties Served: Del Norte,
Humboldt, Lake, Mendocino

North State (530) 895-4027

Counties Served: Butte, Glenn,
Lassen, Plumas, Modoc,
Shasta, Siskiyou, Tehama, Trinity

Sacramento (916) 263-3085

Counties Served: Alpine, Colusa, El
Dorado, Nevada, Placer, Sacramento,
Sutter, Yolo, Yuba, Sierra

North Bay (707) 648-4073

Counties Served: Napa, Solano,
Sonoma

Bay Area (510) 286-0439

Counties Served: Alameda, Contra
Costa, Marin, San Francisco,
San Mateo

North Valley Hills (209) 473-6930

Counties Served: Amador, Calaveras,
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State Council on Developmental Disabilities

www.sccd.ca.gov



Self-Determination Program

What Is It, How Does It Differ from Traditional Services, & Is It Right for Me?



Welfare & Institutions Code 4685.8

“The Self-Determination Program shall be available in every regional center catchment area to provide participants and their families, with an individual budget, increased flexibility and choice, and greater control over decisions, resources, and needed and desired services and supports to implement their IPP.”

A decorative graphic on the left side of the slide features four interlocking gears of different colors (blue, orange, and grey) arranged in a cluster. Each gear contains a black silhouette of a person's head and shoulders, representing a diverse group of individuals. The background is a light beige color.

Guided by that idea that...

People with disabilities should have the ultimate authority to decide how money designated to support them should be spent.



A Little History

In 1998, there were five “Pilot Projects” to test how well Self-Determination works. After three years, they all reported that:

- Everyone was happy and satisfied
- People only bought things they needed and didn’t waste money
- No one had serious problems or had to go to a Fair Hearing
- Everyone in the state should be able to get Self-Determination



With Self-Determination...

- You get a personal ***Budget*** to spend on the things you need for a year.
 - You make a plan and decide how to spend your money.
 - You hire the workers that will help you.
- A ***Fiscal Management Service*** keeps your money safe and pays your workers.
- You can get help from a ***Facilitator*** to make your plan and stay within your budget.



The Five Principles of Self-Determination

1. Freedom
2. Authority
3. Support
4. Responsibility
5. Confirmation



Freedom

- To plan your own life and future
 - To choose who helps you
 - To control the services you use
- To hire your own workers and change when needed



Authority

- To control how you spend the money allocated to you
 - To be the employer
- To set your own standards for services
 - To make your own decisions



Support

- To be successful in the life you choose
 - To be a member of your community
- To make decisions and plan your own life
- To find people you know and trust who will help you



Responsibility

- For making decisions and choices for your life and accepting responsibility for those choices and decisions.
- For using your talents and skills to be as successful and independent as you can be.
- For giving back to others and to your community.
 - For being smart with your money.



Confirmation

- To be a leader and to let others know how Self-Determination can work better for people in the future



More on Responsibility...

- It may be your budget, but it's still taxpayers' money and you have the ***RESPONSIBILITY*** to spend it wisely.
- If there's a problem, it's your ***RESPONSIBILITY*** to handle it.
- You can't ask the regional center to help because it's your ***RESPONSIBILITY*** now, not theirs.
 - You wanted the ***RESPONSIBILITY***, right?
 - The buck stops with you because you have the...



WHO IS ELIGIBLE? HOW DOES IT WORK?

Who is Eligible?

You must:

- Have a developmental disability and get services from a regional center
- Live at home or in the community
 - Consumers residing in a licensed long-term health care facility (Skilled Nursing Facility or Intermediate Care Facility) are not eligible to participate
- Agree to go to a class on how Self-Determination works
- Agree to live within a set budget for a year
- Agree to work with a “Financial Management Service”



Phase-In Period

- The program will start once it is approved for federal funding (end of 2016 or early 2017). Then,
 - The statewide Self-Determination Program shall be phased in over three years, and during this phase-in period, shall serve up to 2,500 regional center consumers, inclusive of the remaining participants in the self-determination pilot projects.



Regional Center	Active Consumers (Status 2) As of August 31, 2014	Percent of State Total	Remaining Pilot Program Consumers by RC	Proposed Number of Participants Per RC	Total (Remaining + Proposed)
Alta California	17,595	7.3%		175	175
Central Valley	14,129	5.9%		141	141
East Bay	15,603	6.5%		155	155
Eastern LA	8,860	3.7%	26	88	114
Far Northern	6,269	2.6%		62	62
Golden Gate	7,322	3.1%		74	74
Harbor	9,826	4.1%		98	98
Inland	24,670	10.2%		244	244
Kern	6,729	2.8%	36	67	103
Lanterman	7,536	3.1%		74	74
North Bay	7,009	3.0%		71	71
North LA	17,514	7.3%		174	174
Orange County	15,616	6.5%		155	155
Redwood Coast	2,936	1.2%	27	28	55
San Andreas	12,748	5.3%		126	126
San Diego	19,403	8.0%	3	191	194
San Gab Pomona	10,422	4.3%		102	102
South Central	10,919	4.5%		107	107
Tri-Counties	9,902	4.1%	16	98	114
Valley Mountain	9,715	4.0%		95	95
Westside	6,792	2.8%		67	67
TOTALS	241,515	100%	108	2392	2500

Full Roll-Out

- Once the phase-in period is complete, self-determination will be available to everyone statewide with no limit on the number of participants.
 - Anticipated sometime in 2019/2020





How It Works – Your Individual Budget

- The amount of your Individual Budget is based on how much was spent on you over the last 12 months.
- The individual budget is determined by the IPP team and the amount can be adjusted, up or down, if the IPP team determines that the individual's needs, circumstances, or resources has changed. The IPP team may adjust the budget to support any prior needs or resources that were not addressed in the IPP
- You decide how it's spent; designate “chunks” of money for service categories
 - Budget pays for FMS (mandatory) and Facilitator (optional)
- With the help of people you trust, you develop a Person-Centered/Individual Program Plan (IPP/PCP) that reflects your vision in the different areas of your life and set goals



How It Works – Financial Management Service

- The Financial Management Service (FMS) is the “bank”
- Your individual budget pays for the FMS. You must use a FMS to be in Self-Determination.
- They keep your money safe and take care of tax withholdings, insurance, and compliance with relevant state and federal employment laws
- They make sure your workers know what they’re doing (verify provider qualifications) and don’t have criminal records
 - They send the paychecks to your workers
- Every month they will tell you and the regional center how much you spent and how much you have left.

****They DON’T tell you how to spend your money!****



How It Works – Independent Facilitator

- Person, selected and directed by the participant, who is not otherwise providing services to the participant pursuant to his or her IPP
 - Helps you with your Person-Centered Plan and your budget
 - Helps plan and maintain the individualized budget
 - Helps you find and hire the people you want to work for you
 - Helps you decide how much to pay your workers
 - Makes sure your workers do their jobs
 - Helps mediate issues with providers
- Helps you find people in your community that are willing to help you for free

** You don't have to use a facilitator. If you do, you pay him/her with your budget money.**



How It Works – The Basics

- Ask for Self-Determination
- Agree to abide by the rules and live within the limits of your individualized budget (IB)
 - Hire a facilitator if you want
 - Hire a financial manager (mandatory)
- With the help of people you trust, develop a Person-Centered Individual Program Plan (PCP/IPP) that reflects your vision in the different areas of your life and set goals
 - Give your PCP/IPP and IB to your FMS
- After background checks are completed, your FMS starts paying the people you hired



How It Works - Services

Q11. Are there restrictions on what the individual budget can be used for?

Yes, a participant can only purchase services and supports as described in the SDP Waiver and in the IPP. Services funded through other sources (e.g., Medi-Cal, schools) cannot be purchased with SDP funds.

www.dds.ca.gov – SDP FAQ’s

- Communication Support
- Advocacy Services
- Behavioral Intervention Services
- Home Health Aide
- Family Assistance and Supports
- Financial Management Service
- Dental Services
- Environmental Accessibility Adaptations
- Community Living Supports
- Crisis Intervention Supports
- Community Integration & Employment Services
- Optometric/Optician Services
- Nutritional Consultation
- Live-In Caregiver
- Lenses and Frames
- Integrative Therapies
- Individual Training and Education
- Housing Access Supports
- Independent Facilitator
- Speech, Hearing, & Language Services
- Homemaker
- Specialized Therapeutic Services
- Specialized Medical Equipment & Supplies
- Skilled Nursing
- Respite Services
- Psychology Services
- Personal Emergency Response (PERS)
- Participant-Directed Goods & Services
- Training and Counseling Services for Unpaid Caregivers
- Technology
- Transportation
- Transition/Set-Up Expenses ⁴⁵
- Vehicle Modifications & Adaptations



EXAMPLES



Traditional Services vs. Self-Determination Example Requesting a Service

Traditional

- Person wants Awesome Therapy (AT).
- Person has tried all programs offered and none meet needs. Person has letters from doctors to back up request for AT.
- Service Coordinator says AT isn't "vendored" and takes request to "committee."
- Person gets a denial letter saying AT isn't vendored, is too expensive, and person doesn't need AT anyway.
- Person appeals denial and could wait for weeks for decision and may lose at hearing.

Self-Determination

- Person wants AT.
- Person makes sure there's enough money in budget to pay for AT.
- Person talks with AT and comes to an agreement about hours & rate.
- Person gives hours & rate info to FMS who makes sure AT has required certification and that staff don't have criminal records.
- Person starts receiving AT.
- Whole process takes a few days.



Traditional Services vs. Self-Determination Example

Requesting a Service

Traditional Services

- Melissa asks for ABA for 10 year old son
- RC says POS guidelines prohibit them from funding
- Melissa's private insurance won't fund (due to self-funded plan)
- Melissa goes to fair hearing
- One year after request, she wins hearing
- ABA finally started, one year later
- RC tries every year to stop funding it

Self-Determination

- Melissa puts ABA therapy into her son's IPP
- Melissa contracts with preferred provider
 - ABA therapy started within a few days
- Melissa decides when to start fading ABA therapy; keeps for as long as son needs it



ROLES & RESPONSIBILITIES



New Roles & Responsibilities: Your Service Coordinator vs. You

Service Coordinator

- Has about 80-100+ people to help.
- Can't tell you "yes" or "no" without asking supervisor first.
- Must follow purchase of service guidelines that emphasize "cost-effectiveness."
- Must pursue "generic services" first.
- Must follow all of the above or could lose his or her job.

You

- Have one person to help: YOU
- Don't have to get permission first.
- Must make sure there's enough money in your individual budget.
- Can purchase generic or non-generic services.
- You can't get fired because YOU ARE IN CHARGE!



New Roles & Responsibilities: Your Budget

Regional Center

- Gets money from the Department of Developmental Services (DDS).
- Money comes in one lump sum for the year and must be divvied out to thousands of people in their catchment area.
- Must spend taxpayer money wisely and cost-effectively based on needs.
- Must keep records of expenditures for reporting purposes.

You & Your FMS

- Your FMS gets your budget money from your regional center.
- You get your money in one lump sum for the year to spend on services for one person.
- Must spend taxpayer money wisely and cost-effectively based on needs.
- Your FMS must keep records of expenditures for reporting purposes.



New Roles & Responsibilities: Service Providers

Now

- Providers are vended and under the legal and contractual authority of the regional center.
- Must provide services according to regional center policies.
- Rates of payment and hours of service are set by the regional center.
- Providers are forbidden to do things outside the scope of their vendor agreement.

Self-Determination

- Workers you hire can be vended, or not, and are under your legal and contractual authority.
- Workers you hire must provide the agreed-upon type and amount of services
- You decide how much they get paid.
- You have the authority to tailor services and set your own standards.



IS SELF-DETERMINATION RIGHT FOR YOU?



Have you lost needed/valued services because of budget cuts?

Many consumers and families had important services taken away in 2009 as a result of the budget crisis. The law was changed giving the regional centers the authority to suspend or limit social and recreational programs, camp, non-medical therapies, and respite.

With Self-Determination these cuts don't apply. You are free to buy things like fitness club memberships, adaptive swimming classes, equestrian therapy, etc. if the service is in your plan and within your budget.

If you lost your child's summer camp, or the respite you and your family depended on, then Self-Determination could be right for you.



Do you get a lot of services?

People with complicated lives who receive services and supports from many different providers face unique challenges, especially during emergencies. Even something as simple as a change of service coordinators can cause a family's house of cards to come crashing down, and the regional center can be slow to respond.

If you have a complicated life that requires creative solutions and quick responses to unexpected challenges, then Self-Determination could be right for you.



Have you had a lot of fair hearings?

The regional center has the legal right to say “no” to any request you make. In fact, given recent changes to the law, they have the right to deny many services more easily now than ever before. If a service is denied by the RC the family member or consumer has the right to appeal – a process that can take months to complete.

With Self-Determination the details are worked out early on during comprehensive person-centered planning sessions, so there is a much better chance that disagreements and conflicts you experienced in the past can be avoided. If you have been forced to appeal regional decisions many times then Self-Determination could be right for you.



Do you have unique needs that require services your regional center doesn't offer?

The regional center doesn't have to pay for a service you ask for just because you think it will best meet your needs. If they feel the service is too expensive and/or another comparable service is available they can offer you that.

With Self-Determination you can buy any service that will meet your needs regardless of cost as long as it's in your plan and you have the money to pay for it.

If you've tried many programs and none of them have worked out, or if you have a program in mind that could be a perfect fit but the regional center won't pay for it, then Self-Determination might be right for you.



Do you want a good-paying job or want to start a small business?

If you ask the regional center to help you get a good job or start a business they will refer you to the Department of Rehabilitation (DOR). It can take DOR months before they offer you something. Or they could decide not to help you at all because you're "too disabled." After all that, you can go back to the regional center and start from scratch. The RC will probably offer you a day program.

With Self-Determination you don't have to go to DOR first or settle for a day program. You can enroll in college, or take a vocational course, or use your money to buy the equipment and supplies you need to start a small business. If you've experienced any of the above, then Self-Determination might be right for you.



WHAT TO DO NOW?



- Think strategically
 - Ask for all of the services you need now
 - Go to fair hearing when denied
 - Learn and share what you know
 - Watch for public comment periods on regulations
 - Sign-up for DDS updates (email sdp@dds.ca.gov)
- Let your service coordinator and support team know you're interested in Self-Determination.
- Learn as much as you can about Self-Determination.



Local Advisory Committee

- Each regional center will establish a Local Advisory Committee (LAC).
- The law says that the LAC “shall consist of the regional center Clients’ Rights Advocate, consumers, family members, and other advocates, and community leaders.”
- The regional center appoints one half of the members and the local SCDD office appoints the other half.
 - A majority must be consumers and family members.
- The LAC must “reflect the multicultural diversity and geographic profile” of the people served by the regional center.
- **The LAC monitors the progress of the SD Program and makes recommendations for improvement to the regional center and DDS.**



COMMON QUESTIONS



- ***What happens if I move to a different regional center?***

You can stay in SD and keep your budget if you move.

- ***What if I want to leave the Self-Determination Program?***

Self-Determination is voluntary. If you choose to leave the regional center must make sure you get the services you had before.

- ***If I leave Self-Determination by choice can I return?***

If you leave by choice you have to wait 12 months to return.



- ***Do I have the same rights under Self-Determination?***

Yes. You have same rights under Self-Determination that you have now.

- ***What if the regional center says I can't be in Self-Determination and I don't agree?***

You can ask for a Fair Hearing. You have the right to appeal any decision you don't agree with.

- ***What if the regional center says my budget is too big and wants to give me less?***

You can ask for a Fair Hearing. You have the right to appeal if you don't think there's enough money in your budget.



THANK YOU!

State Council on Developmental Disabilities