

Department of Developmental Services (DDS)

Consumer Advisory Committee (CAC)

Meeting Minutes

June 11,12 2019

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|--------------------------------|--------------------------|
| <u>Members Attended</u> | Angie Romero |
| | Brian Winfield |
| Deaka McClain | Keith Nelson |
| Rick Hodgkins | Ashley Myles |
| Ryan Nelson | Leah Hollis |
| Esther Kelsey | Sherry Erickson |
| Matthew LaGrand | Hydeia Chatman |
| Kara Ponton | Timothy Schmitz |
| Sara Desumala | Rachelle Gomez |
| Lisa Utsey | Ed Plon |
| Kim Rucker | Jesse Padilla |
| Craig Moorman | Michael Viernes |
| Shawn Costello | Ali Bay |
| Sam Yi | LeeAnn Christian |
| | JJ Fernandez |
| <u>Members Absent</u> | Dante Allen |
| Tim Farrar | Christine Hager |
| Yvonne Kluttz | Lucia Da Silva |
| | Gloria Fong |
| <u>Others Attended</u> | Alex Whedbee |
| Nicole Patterson | Nancy Moorman |
| Jana Chapman-Plon | Dora Moorman |
| Michael Shepard | Yvonne McCuistion Tucker |



June 11, 2019



1. CALL TO ORDER

Deaka McClain, Chairperson, called the meeting to order at 9:05 a.m.

A. Everyone introduced themselves

- During introductions Deaka asked members to answer the question:

✓ “What is the hottest place you've ever been?”

B. The Ground Rules were read by Ryan and Kara

C. The agenda was reviewed and no changes were made.

It was moved (Rick Hodgkins), **seconded** (Kim Rucker), **to approve the agenda.**

D. The minutes of the February 2019 CAC meeting were reviewed. **It was moved** (Rick Hodgkins), **seconded** (Ryan Nelson), **to approve the minutes with corrections.**

2. CalABLE

Dante Allen, Executive Director of CalABLE came to the CAC meeting to do a presentation on the CalABLE program. He started by sharing some facts about people with disabilities:

- 1 in 9 adults have some kind of disability
- 1 in 3 are employed
- 26% of those working make less than \$15,000 per year
- 19% of those working make over \$75,000 per year vs. triple that for people without disabilities
- 55% of people with disabilities who have to come up with emergency money of \$2,000 wouldn't be able to come up with it
- Half of all people have skipped medical treatment

- Twice as likely to be unbanked (don't have a bank account):
 - ✓ Means that they pay twice as much to deal with a bank, or get a check cashed, because of the fees charged.
- Able Act, passed in 2014, added a new section to the IRS code (529A).
 - ✓ Tax-advantaged savings and investment programs for people with disabilities
 - ✓ Will not affect eligibility for SSI or Medi-Cal
- California's act, which mirrors the federal law, was passed in 2016 and took until 2018 to get it up and running
 - ✓ CalABLE office mission: To meet the diverse needs of our customers and their families. We pledge to be customer-driven, accountable, and a trusted partner in providing financial services.
- CalABLE Eligibility:
 - ✓ Must be eligible for SSI, SSDI, **or**
 - ✓ Self-certification: diagnosed by a qualified physician with a physical or mental disability resulting in marked and severe functional limitations that is expected to last at least one year.
 - ✓ Condition is listed on Social Security Administration's List of Compassionate Allowances or Blue Book Listings
- Contributions:
 - ✓ Before ABLE: couldn't save more than \$2,000
 - ✓ Now: Can save up to \$15,000 per year and up to \$100,000 in total before SSI is impacted
 - CalABLE will automatically reject contributions over these limits
 - ✓ Third parties can contribute to your ABLE

- account and SSI won't even look at it.
- ✓ SSDI: no limits on how much you can save
- ✓ Income from a job is still income. ABLE is not a tax shelter for income.
- ✓ A gift of money is not currently tax-deductible in California for the person who gifted the money
- ABLE to Work
 - ✓ Permits working account owners to contribute above the \$15,000 annual contribution limit, if they or their employer are NOT contributing to a retirement plan.
 - Can contribute an amount of their gross salary or \$27,000
- Basics:
 - ✓ Can only have ONE ABLE account at a time
 - ✓ The beneficiary is always the owner of the account
 - ✓ Can be opened by the beneficiary or an Authorized Legal Representative (parent, legal guardian/conservator, Power of Attorney)
 - ✓ Accounts are asset protected: they cannot shelter income. Any income is still seen as such by benefits providers (SSI, Housing, etc)
 - ✓ Functions both like a savings and checking account
 - ✓ Funds are tax-exempt as long as they are spent on "Qualified Disability Expenses" (QDE)
 - Anything that impacts your health, independence, or quality of life
 - Categories are intentionally broad (education, housing, transportation, health care expenses, and more)

- Non-QDE: Not illegal, but it is subject to regular income taxes, plus a 10% tax penalty (plus 2% in California) on account earnings and benefits may be at risk (might be considered a resource)
 - Keep records of any money you spend from your ABLE account
 - Only cash can be moved into an ABLE account (not property or retirement accounts)
- Federal Tax Reform Changes to an ABLE Account
 - ✓ Allowed college savings accounts to be rolled over to ABLE accounts
 - ✓ Access to Saver's Credit
 - ✓ Contributions limited to \$2,000 per beneficiary
 - ✓ All 3 of these end after 2025
- CalABLE vs. Special Needs Trust
 - ✓ Complementary tools that make up a broader financial planning strategy
 - ✓ Advantages of ABLE Accounts:
 - Inexpensive to set up and maintain
 - Can be used to pay housing expenses without affecting SSI
 - Tax-advantaged status
 - Beneficiary has more control over funds
 - Can open the account at any age (assuming disability started before age 26)
- Features and Benefits
 - ✓ Low fees
 - ✓ Free, easy online enrollment
 - ✓ Electronic contributions/deposits/fund transfers, or by check
 - ✓ E-gifting
 - ✓ Prepaid debit card (coming in July): be sure

to keep a record of how that money was spent

- ✓ If you're paying rent from ABLE account, you must use money withdrawn from ABLE within 30 days or HUD will view it as income or extra resources
- ✓ Excluded from household assets
- ✓ Not considered income or wages
- Simple Investment Options
 - ✓ Funds managed by TIAA-CREF
 - ✓ FDIC-Insured Portfolio
 - ✓ Conservative Portfolio (less likely to gain money, but less risk)
 - ✓ Moderate Portfolio
 - ✓ Aggressive Growth Portfolio
 - ✓ Can change investment options twice per year
 - ✓ Choose investment options online
 - ✓ Can allocate funds to different options
- Sign up online on CalABLE website
- Fees:
 - ✓ \$37 per year annual account maintenance fee (12 equal monthly installments (about \$3 per month))
 - ✓ Investment fee: 0 to 0.1%
 - ✓ State administrative fee: 0.44% (pays for CalABLE staff)
 - ✓ Paper statement mail delivery fee: \$10 per year
 - ✓ Insufficient funds: \$20 per occurrence
 - ✓ Check issuance fee: \$5 per check
 - Electronic transfers are free
 - ✓ Online enrollment is free
 - ✓ \$25 minimum deposit to open account
- Married couple (both disabled) would have 2 separate accounts (only 1 beneficiary per account)

- Handout packet: all enrollment documents
- Account withdrawals:
 - ✓ Log into your account and request withdrawal
 - ✓ No limit on number of withdrawals
 - ✓ Can transfer electronically to checking or savings at no charge or request a check for \$5.00
 - ✓ Prepaid (loadable) debit card: can transfer funds to the card
 - ✓ CalABLE will not ask what you spend your money on, but IRS and SSA have authority to audit so keep your receipts
- Contact information
 - ✓ CalABLE Customer Call Center
 - Monday – Friday
 - Open 9:00 a.m. to 5:00 p.m. PST
 - [833-Cal-ABLE](tel:833-225-2253) (833-225-2253)
 - CalABLESupport@CalABLE.ca.gov
- Help spread the word about ABLE

3. **COMPLAINTS PROCESS**

Lucia Da Silva from DDS came to the CAC to talk about DDS's Complaints Process.

- Early Start
 - ✓ A person has a year to file a complaint from the time the violation happened under federal law
 - ✓ Title 17 expanded the timeline to submit a complaint to 3 years if asking for a corrective action plan
 - ✓ DDS has 60 days from the date the complaint was received to make a determination
- Welfare & Institutions Code Complaints
 - ✓ Violation of rights
 - ✓ Filed with regional center first. The regional

center must answer within 20 days. Then it goes to DDS.

- ✓ DDS has 45 days to issue a decision
- Whistleblower Complaints
 - ✓ Can be anonymous unless the complaint is about abuse
- Citizen Comments and Complaints
 - ✓ All other complaints or to recognize an individual, regional center, or service provider
 - ✓ Positive feedback goes to the regional center

4. **CAC INPUT ON DDS WEBSITE**

Gloria Fong and Alex Whedbee from DDS came to the CAC to get input on the new DDS Website. Gloria went over the new website design and the new features. The CAC also gave some ideas on a new name for the Consumer Corner. Gloria asked the CAC members to take some time after the meeting to review the DDS Consumer Corner website and give their input by July 5th. The new website should be rolling out mid to late Summer.

5. **MEMBER SPOTLIGHT**



The CAC officers: Deaka McClain, Ryan Nelson and Kara Ponton. Each of them shared their answers to the following questions with the CAC members:

- What made you get involved with advocacy work?
- Who is your biggest supporter? How do they encourage you to keep going?
- What would you tell your younger self as an advocate today?
- What would you say is the hardest part about being an advocate?
- What would you like to be doing in five years?

- Anything else you would like to share with the group?

Each member will have a chance to answer the same questions at a future meeting.

6. **COORDINATOR OF CONSUMER SERVICES REPORT**

Nicole gave a report on changes that have taken place over the last several months.

- Nicole's position was a Governor Appointee position and now she is a regular civil servant position
 - ✓ Some things in Nicole's job may change, but the CAC will stay under her.
 - The CAC will still meet in Sacramento twice a year and once on the phone.
 - ✓ Nicole's title may change, but it hasn't been decided yet
- Nicole has moved to a new office at DDS called the Quality Management Section
 - ✓ Our new supervisor is Joshua Sudarma
 - ✓ We're in the section that does the SafetyNet website, National Core indicators and other projects
 - ✓ Please do not call Angie anymore because she is no longer our secretary
- The CAC has a new email address now:
CAC@dds.ca.gov
 - ✓ If you're talking to people about CAC business, you can give them this email

The Office of Human Rights is still willing to help us if they get any phone calls for us, but Nicole is relying on committee members to pass the word.

7. COMMITTEE VACANCIES

When there are vacancies on DDS committees and boards, and Nancy would like CAC participation, who is interested in receiving a call from Nicole? Meetings may be in Sacramento, on the phone, or in different parts around the state. CAC members shared their areas of interest:

- Kim (HCBS/policy)
- Shawn (Employment/disabled rights)
- Craig (Recreational activities)
- Ryan (Housing/policy)
- Deaka (HCBS/policy/housing/accessibility)
- Sara (anything in the Bay Area)
- Youth and Advocacy: everyone listed above plus Sam are interested in this topic
- Nancy M. is interested in committees that need a parent voice

There is a vacancy coming up on the QA NCI committee because Kara is terming out. Meetings are twice a year in summer and fall. These are one day meetings from 10:00-2:00. You can come in the night before depending where you're coming from. Those interested are:

- Kim
- Ryan
- Shawn (maybe)
- Craig

For those terming out there may be opportunities for them on committees

- Rick is interested in rate study

8. Budget Update

Brian Winfield came to the CAC to give an update on the DDS budget.

- Increased rates for service providers: neither the

Senate or Assembly plans met everything wanted. Conference committee reached an agreement. Rate increase will be Jan 1, 2020 of \$125 million dollars then it will increase again in 2021 to \$250 million dollars. Then after 6 more months an additional \$150 million dollars

- ✓ Will go to targeted providers
- ✓ Senate voted on across the board increase
- ✓ Some increases will be targeted and some will be across the board
- ✓ Legislature has taken notice of all of the advocacy and allocated more money
- Uniform Holiday Schedule: went to conference committee. It was suspended for the last 2 years and will be suspended for 2 more years.
- \$1 million for regional centers to pay deductibles for early start
- \$2.1 million for minimum wage increase Jan 2020 to \$13/hour
- Regional centers are getting funding for positions for services for foster youth
- Funding for regional center staffing for family home agencies and development of the service (resource development, monitoring, and oversight)
 - ✓ Family home agency: a family is certified by the regional center to provide a home for up to 2 individuals
 - ✓ The person integrates with the family and really becomes part of the family
 - ✓ People are very happy with this model of service
- Regional center staffing for monitoring of medical model homes
 - ✓ Serve complex needs for consumers
 - ✓ Receiving funding for more staffing
- Specialized caseload ratios
 - ✓ 1 caseload manager to 25 people for specialized

care or crisis

- Developing additional acute crisis home
 - ✓ 10 crisis beds at Porterville
 - ✓ 2 homes in community of 5 beds each (transition from Porterville)

9. **ASK DDS**

LeeAnn Christian let the CAC know that DDS is going through a reorganization and determined that there's more work to do in the community. What are the priorities for the Department's work? How can DDS be more accessible to individuals served?

- DDS is getting new positions. Hiring more staff to:
 - ✓ Expand Quality Assurance (QA) and Quality Management Section (QMS) to work on better outcomes
 - ✓ Improve Risk Management (RM) system
- Regional Center teams:
 - ✓ Now have 4 liasons
 - ✓ Will have 3 people for every 3 regional centers to go to committee meetings
- What could the regional centers or DDS do better?
 - ✓ Bring regional center caseload ratios down
 - ✓ RC client advocates should not be part of the regional center management team
- Remove the cumbersome internal utilization committees: we were promised that those would be temporary (ILS/SLS, DME, etc) and disappear once the budget improved. These should be decisions at a planning team meeting.
- If a person is unhappy with their services, can they go to another RC?
 - ✓ Need to receive services from a regional center where you live
 - ✓ DDS wants to hear about situations that make you unhappy

- Service coordinators are being given extra people on their caseload with SDP participants at some regional centers.
- Is there any way that DDS can encourage ARCA to have clients on their full board?
 - ✓ DDS has no authority over ARCA, but can talk to them about it
- The Lanterman Act needs to be fully funded
- Hold more community forums to be more transparent
- Big turnover at regional centers: need more regional center operations funding
- Better access to healthcare



June 12, 2019

1. CALL TO ORDER

Deaka McClain, Chairperson, called the meeting to order at 8:31 a.m.

- During introductions, Deaka asked members to answer the question:
 - ✓ "What is your favorite ice cream and why"?

2. CAC MEMBER REPORTS



The following members gave reports on what they have been doing on behalf of the committee and their People First and/or local self-advocacy groups: Rick Hodgkins, Matthew LaGrand, Deaka McClain, Ryan Nelson, Kara Ponton, Yvonne Kluttz, Esther Kelsey, Craig Moorman, Kim Rucker, Shawn Costello, Lisa Utsey, Sam Yi and Sara Desumala.

3. HOUSING

Yvonne McCuiston Tucker from DDS came to share where DDS is on the housing mission. First, she went over Governor Newsom's FY 2020 plans to expand California Housing projects

- The Department of Developmental Services (DDS) resource development plans, including priorities under the Community Placement Plan (CPP) and Community Resource Development Plan (CRDP) resource development priorities.
 - ✓ How you can be a part of a solution to create/expand affordable housing for individuals with ID/DD.
 - ✓ Increase housing planning and production loans and grants, including to local government.
 - ✓ Increase housing funding for the development of mixed-income housing.
 - ✓ Use excess state property for developing innovative housing projects.
 - ✓ Increase housing planning and production loans and grants, including to local government.
 - ✓ Increase housing funding for the development of mixed-income housing.
 - ✓ Use excess State property for developing innovative housing projects.
 - **Goal #1:** Expand the availability, accessibility, and types of services and supports to meet current and future needs of individuals with ID/DD and their families in the community.
 - **Goal #2:** Develop systems to ensure that quality services and supports in the least restrictive environment are provided to individuals in the community.
 - **Goal #3:** Develop services that are person-centered and represent the

diversity of Regional Centers catchment areas.

- Developers know very little about people with disabilities
 - ✓ DDS has a plan to create exposure and that the CAC could take statewide to create this exposure
 - ✓ Need to see the money in these units
- Need to see an ongoing funding source for housing for people with disabilities
- There is huge concern about individuals who live with aging family members
- CPP: resource development for those moving out of a developmental center (DC) or those at risk for going into a DC. Aside from that, there hasn't been money to create resources for housing options for those who already live in the community.
- New: CPP/CRPD
 - ✓ The funds left over after CPP dollars are exhausted can be used for CRPD
- Need to learn what the resources are that are needed in the community
- Governor has a plan to control rent increases, but no details yet
- DC's will all be closed soon (except Porterville secure treatment). There are only about 10-12 people who haven't been found placement yet. By 2022 we won't have institutional settings anymore.
- CPP funds will be transferred over to CRPD

4. **DRESS CODE:**

Due to time and technical issues, we will table the Dress Code discussion until November

5. **UPDATED DOCUMENTS FOR END OF LIFE PLANNING**

Christine Hager from the office of Clients' Rights and Advocacy Services came to the CAC meeting to continue the conversation about updating the My Life My Way at the End. The Coalition for Compassionate Care put together a new version of the My Life My Way at the End. It was recommended using the Making a Plan Thinking Ahead workbook instead of updating the My Life My Way at the End. Also, on the Coalition for Compassionate Care website there was another document that was also included in the CAC packet that is an actual Advanced Directive document that people can fill out. This is available in many languages.

- CAC's input and approval, Christine and Lisa will work together to create a self-advocacy training based on these publications.
 - ✓ Everyone should be talking about end of life plans in their IPPs. They can't respect your wishes if you don't tell them what they are.
 - ✓ The goal is to get as many advocates trained as possible
 - Conferences
 - Small group trainings in each area

The CAC decide to move forward on Christine and Lisa creating a training.

Next steps:

- Develop the training
- Before the November meeting Lisa and Christine will have a draft ready for members to review.
- Final approval and training at the November CAC

meeting

- Once approved: Clients Rights Advocates (CRAs) will be trained
- By June of next year this should be rolling and CAC members and CRAs can work together doing training in their communities and share how it's going.

6. **MEETING DATES AND LOCATION**

Nicole went over the CAC meeting dates for 2020.

- Please note that the November 2020 meeting will be on Wednesday and Thursday instead of Tuesday and Wednesday, due to a holiday that week.

CAC members discussed whether they wanted to stay at the current location or choose another one?

- Beds are too high, threshold bump, phones in wrong location, difficult to maneuver in rooms
- Nicole asked everyone to think about food options and how you're being treated
- Water gets all over the floor when you shower
- For transportation, also must consider travel time to and from the airport
- There are financial considerations too such as if the hotel is willing to serve us at the state rate
- When Nicole is looking for other hotels, she will look at the accessible rooms and try to figure out the food situation
- Nicole will bring a list of hotels that meet the requirements

Nicole let the CAC know that many hotels book a year in advance

- The plan is to book the Crowne Plaza for June 2020 and look for another hotel for the November 2020 meeting.

Keith let the CAC know that he is part of the Hospitality Association and if they want someone in power to hear

the feedback, he can help to invite someone from that organization.

7. TRAVEL CLAIM PAPERWORK

Nicole Patterson took some time to talk to the group about travel paperwork.

- Room receipts: make sure you get a room receipt with a \$0 balance at the bottom. If you have a roommate, please write their name on the receipt.
- Parking receipts need to be for the least expensive lot, and DDS will check to make sure that you parked in the least expensive option.
- Rental cars: Need rental car agreement (pink paperwork) and a receipt when you return the vehicle. If you don't have both of these papers, you will owe money.
- Support claim: This is how facilitators get paid for providing support for the member. You have to put in dates, what you worked on, and where you met. You are approved for 2 hours per month. You must get pre-approved by Nicole if you will need more than 2 hours per month of support time.
- Shuttle: If the hotel offers a free shuttle you must use the free hotel shuttle. The only exception is if you need accessible transportation.
- Get an envelope from us to mail in the paperwork and receipts.

8. COMMUNITY ASSIGNMENTS

CAC members were asked to work on the following:

1. Networking

Do one presentation in your area on any of the CAC publications

2. California Achieving a Better Life Experience (CalABLE) Account

Please share the information you learned about the CalABLE Account and how people with disabilities can use it. The PowerPoint has been included in this packet for your review, as well as a few CalABLE brochures to give out.

3. Complaint Process

Share copies of the Appeals and Complaints sheet. The PowerPoint has been included in this packet for your review.

4. Input on the DDS Website

Gloria would like you to review the DDS consumer website at <http://www3.dds.ca.gov/consumers/> and then answer the questions using the following link:

https://www.surveymonkey.com/r/DDS_CAC_Review

We will need this information by July 5th. If you need any assistance, please call Nicole.

5. Housing

Help raise awareness about the need for housing for people with developmental and intellectual disabilities. The Housing PowerPoint has been included in this packet for your review. Here are some ideas on how to get the word out:

- Write letters to your local representatives
- Participate in local government Housing public meetings
- Using social media



9. END MEETING

Deaka McClain, Chairperson, adjourned the meeting at 3:06pm.