

PUBLIC MEETINGS 2024
MINUTES
I

Date: February 24, 2024, at 1:00 PM

Location: La Familia Neighborhood Resource Center
22366 Fuller Ave, Hayward CA 94541

Language: In Spanish

Number of Attendees: 14

Actions to improve attendance and participation: The meeting was held in collaboration with La Familia Counseling

Comments and questions from families

- In my opinion, some families do not receive services when their children are minors because parents feel obligated to pay for services. The school also covers the costs of some services when they are minors.

- I would like to share my experience with recreational services. I think it's better if the agencies first become vendors for the Regional Center to provide the services. I became a vendor for my daughter to receive recreational swimming services, but when I send receipts for what we paid for these lessons, the regional center takes too long to reimburse, which I don't think is fair. I think there are a lot of parents who don't have the opportunity to become vendors themselves and pay the amount for recreational services and then wait for this refund, even more so knowing that they take too long to process it. The RCEB keeps giving me excuses why they haven't been able to reimburse me.

- ¿What can families who don't have the money do to become vendors, then pay for recreational services and wait for reimbursement? Our community doesn't have the funds to pay and wait for the money to be reimbursed.

- My daughter is in the Self-Determination program and her budget for services is already in shape, she was approved in ILS and we still haven't found a worker who can give us this service. The FMS has complicated the process a lot, they took a long time to respond, although I am constantly following up, they are not quick to give me an answer. My concern is changing agencies because I don't want to start over because the process has been very stressful. I'm trying to do the ILS service directly with the MANOS agency, but they can't find a worker for my daughter. Previously I tried to find the worker myself and I was unsuccessful, that's why this time I tried through an agency, but I still have no worker. This process of self-determination has been very complicated for us parents.

- Weekend recreational programs would be very beneficial for older clients. There used to be camp programs. It would be nice if there were more information about the camps that are available.

- I see the disparity between whites and Hispanics, in that Latinos don't get any other services beyond Respite. As parents, we must learn from the other programs and services available.
- I think another difference in that there are fewer purchases by Latinos is that when white adults turn 18, they are taken to live in residences, and Hispanics don't like it when children go to live in residential homes.
- I would like ILS and SLS services to be offered from the time children are younger, so that from a young age our children can learn to do things for themselves.
- Another reason there is a disparity between white and Latino adults is because Latinos protect their children even when they are older.
- I would like to know if you train the Case Managers to be able to provide the available information, since they do not explain to us parents about the services available.
- My brother is in the Self-Determination program, and I'm worried that he's not going to get services anymore. In 2 weeks their first year is coming to an end and they still haven't approved the new budget. Since October we have been sending communications to the Regional Center to see about their budget for the second year, but we have not had a good response, they take a long time to answer us. I'm worried that the FMS is no longer going to have money available for its services. In November, they created the new contract. And in November, they created a new contract. We had to contact the DDS to help us. It is not fair that the mistakes they are making on the part of the RCEB are limiting access to the Self-Determination program. Many families do not have the support of being able to call and find out with the agencies, in the case of my brother, I am the support of my mother, and the one who helped him to be making calls to move the process forward. How can we make RCEB and FMS more effective? Because there are a lot of problems with accounting that are reflecting a lot of mistakes. How can we make accounting more effective?

II

Date: February 28, 2024, at 6:00 PM

Location: Zoom

Language: English – For African American Families

Number of Attendees: 15

Actions to improve attendance and participation: The meeting was held in collaboration with The West Contra Costa Public Education Fund and Care Parent Network

Comments and questions from families

- Thank you for hosting this Public Meeting
- It took almost a year for my child to start receiving services from RCEB. It was disappointing that I could not find services in West Contra Costa. All resources are located too far away.

- Does RCEB provide services to deaf/hard of hearing consumers?
- Do you have breakdown on how the money was spent, or what kind of services were used, such as respite?
- How was information for this meeting shared with the African American community?
- My Case Manager does not communicate with me about resources available.
- I would like a Newsletter for African American families.
- A vendor for RCEB clients who are on Self Determination Program should not be allowed to deny services that are offered to others.

III

Date: March 8, 2024, at 5:30 PM

Location: ZOOM – Luminous Pathways

Language: Presentation in English

Number of Attendees: 12

Actions to improve attendance and participation: The meeting was held in collaboration with Luminous Pathways, an organization receiving funds from the LACC grant from RCEB.

Comments and questions from families

- Are clients and families resisting to access services? How can providers and CBOs help clients to access services?
- Why are there differences in expenditure between White consumers and consumers from other races?
- Are families receiving information during the IPP?
- What happens with the funds for authorized but not utilized services?

IV

Date: March 9, 2024, at 4:00 PM

Location: FCSN

Language: Presentation and Power Point in Chinese. Translation to Cantonese & Mandarin

Number of Attendees: 19

Actions to improve attendance and participation: The meeting was held in collaboration with Friends of Children with Special Needs, a service provider to RCEB consumers and a CBO receiving Service Access and Equity funds.

Comments and questions from families

- Why are there differences in expenditures in each age group? Shouldn't expenditures be similar?

- Why the demographic data for the general population is not reflected in the demographic data at the Regional Center?
- Rates have an impact of services not being utilized.

V

Date: March 20, 2024, at 10:00 AM

Location: ZOOM

Language: Presentation in Spanish

Number of Attendees: 22

Actions to improve attendance and participation: The meeting was held in collaboration with Congreso Familiar.

Comments and questions from families

- Why don't many adults get services?
- Do you plan to present POS Expenditure for people in the self-determination program at another meeting?
- People don't want to get into the self-determination program because there are a lot of complaints about the program.
- The Regional Center has its own vendors. Can I choose my FMS (Financial Management Services) or should I accept the one assigned to me by the Regional Center?
- Sometimes services are not used because there are no vendors offering them
- What can we do when we wait for months and months for FMS approval?
- Are all clients without POS with an Enhanced Case Manager? Or are you planning to hire more Enhanced Case Managers?
- Lisa's presence (Executive Director) makes me think I'm being heard. I have an adult son and my Case Manager sent me a letter telling me that he had been transferred to another Case Manager. I haven't received copies of IPP in two years. My new Case Manager warned me, but I never heard from her again.
- "I received home respite but the hours I'm getting aren't enough. What can I do to increase my hours?"
- In what other situation, besides work, can you ask for an extension of childcare? For example, when I'm taking classes.
- I have two children who are clients of the Regional Center. I was given 40 hours of respite for both, but the POS is only in the name of one of them. What can I do to get POS for both?
- There is a virtual computer and English program, given by the University of Fresno from 6 to 8 pm. Can moms be supported with childcare while they take the class?
- My daughter is 1 year and 4 months old. Can I get respite service?
- Who qualifies for respite away from home?
- Can I choose someone from the family, such as an aunt or cousin, to offer the respite service?

- What is IHSS?
- The East Bay Regional Center's website is very complicated to navigate. Other regional center websites are easier to navigate.
- What can we do when the Case Manager doesn't respond to us and what can families who don't have a Case Manager do?
- I hardly see them giving training at RCEB. In other regional centers there are more trainings
- Where can I find the name of my Case Manager's supervisor?
- My daughter is 4 years old and has not received services for 1 year.
- What can parents do when regional center staff give us misinformation?
- Case Managers Need More Training
- I came to RCEB to pick up a hard copy of the application. The receptionist told me that RCEB does not provide paper copies of the application. I have come to RCEB 3 times and in none of those times there was a receptionist who spoke Spanish.
- My child was accepted by RCEB last year and they have changed my Case Manager 5 times already. I notice that the Case Managers are not properly trained.
- Case Managers need better training and better salaries.

VI

Date: March 21, 2024, at 10:00 A M

Location: ZOOM – La Familia

Language: Presentation in Spanish.

Number of Attendees:

Actions to improve attendance and participation: The meeting was held in collaboration with La Familia Counseling, a service provider to RCEB consumers and a CBO receiving Service Access and Equity funds.

Comments and questions from families

- Hispanic or LatiNex families have the lowest per-person authorized services compared to other ethnic groups, and particularly the largest difference compared to white consumers. Why is there such a large discrepancy and what is the regional center doing to close such a large discrepancy.
- When families contact us, they tell us that the reason why they don't use services is due to lack of information. There are communication problems between Case Manager and the parents about filling out the paperwork or to find a provider until they just give up, which contributes to the statistics we've seen.
- I did not know that RCEB would pay for wipes, globes, and napkins for my son. I just learned about that recently and I think sometimes, the information is not available and for that reason one does not ask for help. We applied for intensive therapies for my son, unfortunately those are not available in the area where I live. My insurance does not pay

for the service and for that reason we were going to pay out of pocket. However, a friend told me that through exceptions, RCEB could help with the payment either for some or for the full amount. The Regional Center communicated to me that, indeed there are sometimes when they have paid for the therapy, but because my son is in a home hospital it is the school district that is obligated to pay for the service. In the end, the School District paid for the service. I learned that through exceptions the RCEB can help me cover some expenditures that I was not aware of.

- As a mother leader I hear other mothers saying that they don't have sufficient information about available services for their loved ones. And I think, Case Managers are not informed themselves about available services. When I spoke with the person in charge of the Self Determination Program, she stopped me and said that we don't qualify or that we need so many things. I'm speaking from my own experience. This type of answers is very discouraging and takes away your desire to continue advancing. What I and other mothers do is to change our Case Manager. Yes, we must help but this is a Systemic problem, it is a problem how unprepared are those who are there to help us.
- One of the reasons Hispanics don't use regional center services is that they may use generic services. But also, those who use regional center services have access to the same generic services. If the regional center already has the data, how are they using this information to thoroughly investigate the cause of so many unused regional center services across all ethnic groups? I would like to know when was the last time they met with their Case Manager and wrote an IPP? What efforts are being made with Case Managers as well as what outreach is being made to identify the reasons why they do not use regional center services?
- What is the process DDS follows to select customers with zero POS to receive enhanced Case Management?
- I would like those who do the assessments to be better prepared to make the diagnoses for the regional center and to treat with respect and dignity the children and parents who are there to seek qualification for services from the Regional Center.
- My son needs the respite service, but I've been waiting for more than a year. I'd like to see that improve.
- I had a little problem myself with getting my son to enroll at the regional center The emails that the lady sent me could not be filled because I was not allowed to write on the box. She sent me the same form 4 more times until I spoke to her again. I said, please, send it to me via post office. Only then I could fill out the form, but it took more than a month to solve this problem. The same thing has been happening to me every year and I would like you to see if you can try to update that system. What can you answer if you are unable to see the question?
- Could you put your contact information so that we can, if we ever must ask for help with the people who are there, such as OCRA representative and Elvia Rodriguez from the Regional Center so that we can also communicate with you if we need to?
- Make the regional center website a little easier to navigate because it's hard for me.
- Just 2 weeks ago we received notification that Luna, our daughter had been accepted as a client at the regional center. Then they sent us the information of our case manager and we talked to her, and she gave us some information. It seems to me that the meeting was very short. Because I feel like the Regional Center has a lot of information. She told us

that she was about to enter another meeting, with other people, but the information she gave us was very useful. My question is how can you support us with the situation we have with our little girl?

In the school district, she has on the IEP speech therapy. However, since December, there is no speech therapist in the school district. The speech-language pathologist was absent due to maternity leave, so they only sent us a note saying that she was absent. And so, we were left without a therapist. No one ever covered for her. And my daughter, to date, is without her therapist. We were told we could fix it through medical insurance. We're trying to renew it because it's deactivated, so that's why we can't get speech therapy through them. We talked about this to our Case Manager, and they told us that they don't have this therapy service. Could this be an exception? so that our daughter can, through the Regional Center, receive these therapies, since neither the district nor Medi-cal offer them and because these therapies are very necessary for my little girl. She tries to explain herself, but we know she needs professional help. So, this may be an exception for my child to be eligible for speech therapy, or what do you say?

We have also sent communications to the special education supervisor in the district, but they don't respond to us, they just tell us that they are going to schedule a meeting, but they don't follow through. So, we just asked for a meeting to open an emergency IEP, but we are waiting for them to respond.

- My question is: every year we change our Case Manager? Or what is the reason for them to change them?
- Is there a time limit to be without a case manager?
- Does La Familia, have authorization to approve services and sorry you don't know much about that?
- I have noticed that on the RCEB website they have the directory of all the Regional Center staff, but that does not include the names and contact numbers of the Case Managers of La Familia.
- I see that there are 21 of us right in this call, but I think this is the second meeting in Spanish.
- I have the first appointment, on April 2nd, after that appointment. How long does it take to get started with services?
- How long does it take to be admitted to the Regional Center? A friend of mine applied a year ago to start the regional Center process and it's been a year, and they haven't responded. In those cases, who do I have to talk to or who does she have to talk to?
- We, as parents, how are we going to know that we are filling something wrong if they don't communicate with us? They could just say, you know what ma'am? You didn't fill this part in.
- Another problem that many moms have is trying to communicate with our service coordinator. It's very stressful because we're talking to them, communicating with them, leaving them emails talking every day, but they don't communicate with us afterwards. There, what can be done? Who do we need to talk to? Talk to you?
- What the law says is, after applying to the Regional Center, the Regional Center has 15 business days or 15 business days to file the first appointment, which is what they call the intake and get information. After that they have 120 days, not days of work, but days

to decide on whether they qualify for the regional center or not. Obviously, there are many factors that can cause it to take longer, and some of those may be as Mrs. Elvia said, they are waiting for documentation from the parents, or they are waiting for information from other agencies when they are requesting it themselves. Still, that's what the law says about the timeline.

- To solve translation problems, it would be possible for the regional center to use translator devices, as in clinics and hospitals, or would it be too expensive.

VII

Date: March 26, 2024, at 1:00 PM

Location: ZOOM – Regional Center of the East Bay

Language: Presentation in English

Number of Attendees: 13

Actions to improve attendance and participation: The meeting was posted on the Regional Center website and announced at different meetings.

Comments and questions from families

- I'm curious what are the current outreach efforts, the regional center is doing to focus on monolingual or bilingual Asian families.
- Perfect. Thank you so much. You gave me some ideas. I'll look at those translated brochures. I can add it onto our multilingual site, too. We are promoting the families, but I'll reach out to you both. But thank you for answering my question.
- I want to play off a little bit of the previous question on one part, and that is, we've had some instances of people who especially participants who are sign language based or who use sign language. And I was just wondering if there are resources for organizations that we can tap into. So, we can help staff interact with some of our participants who do use sign language. And then the other piece, it's a separate question. I was particularly fascinated by the slide with the grants and creating greater diversity inclusion. The bias training things like that, and I was hoping for further elaboration on that slide.
- Just further clarification. Some of our participants at our program they're not deaf, but they're nonverbal, and they do use sign language, so is it only for deaf people, or it would it be.
- So just this further elaboration, we are going to be diving a little bit more back into using, having a specific class associated around teaching our participants. We've kind of incorporated it into all our classes. So that's not really where the issue is I'm thinking about. We have a couple of participants. They will type out on their cell phone. In some cases, they don't have a communication device per se. We have one participant who is autistic, and he signs. And there are basic signs that I understand, and other staff understands. But there are just a very small group. If anyone who really can communicate in a fuller way with them, and we can always meet hit these persistent needs. But it's not just this participant. It's also we've had instances where someone has come to us and said, hey, we'd be interested in your program. But this person only

speaks with signs. And so, they really want to be able to sign back and communicate more fully back and not just use a communication device. So that's the reason why I'm asking. And in each of these cases the person is not deaf. So, it's just, it's what they're using or what they're used to using. I'm not too sure what the reason is as to why everyone doesn't use a communication device other than it's not their preference. So, is there someone that we can speak with to follow up with on this? And then we can pursue this a little bit better that way.

- Well, I'm glad you're making that initiative, because I've talked to a few participants. Outside of it. Ability Now that have said that there's a disparity in the financial support that they've given versus some of the other communities or the other people that they talk to. So, it's good that you're taking it on yourself and taking the initiative to evaluate that. So that there is that, so the disparity is shrunken.
- Yeah, I think that's true. But what you find is usually when they're talking about it, it's a 30-year-old talking to a 30-year-old. So, their perspective is like you said, it's the same group talking to the same group. They're not talking to the 50-year-old, who has different needs. I'm really fascinated just by the directions that you guys are going into like the diversity and inclusion and things like that. And if we wanted to just follow up to constantly hear about what's coming down the line along these ends, how would we find out more information.

VIII

Date: March 26, 2024, at 3:00 PM

Location: ZOOM

Language: Presentation in English. Translation into Vietnamese Power Point in Vietnamese

Number of Attendees: 16

Actions to improve attendance and participation: The meeting was held in collaboration with Helping Hands East Bay a service provider to RCEB consumers from various ethnicities and a CBO receiving Service Access and Equity funds.

Comments and questions from families

- Families who are attending by phone don't know how to access the interpretation feature.
- We need to educate the community on how to use zoom and the interpretation feature by phone.
- Many parents called to report that they were unable to join by phone or by computer.
- How many people with autism has been there in the regional center?
- How many Asian people have been in the regional center?

IX

Date: March 27, 2024, at 3:00 PM

Location: ZOOM

Language: Presentation in English. Translation into Cantonese Power Point in Chinese

Number of Attendees: 10

Actions to improve attendance and participation: The meeting was held in collaboration with Helping Hands East Bay a service provider to RCEB consumers from various ethnicities and a CBO receiving Service Access and Equity funds.

Comments and questions from families

- The data presented for the language this year. It seems like you put together Cantonese and Mandarin as one group, and in previous years. You were segregated into Cantonese only, and Mandarin only. So, I wonder if it's just the charts or the actual. I haven't seen the actual like pos report and whether in those report the numbers would be divided among the different language, because Mandarin Chinese is different than Cantonese, Chinese.
- From what I understood it seems like the Asian and Hispanic communities are among those that receive at the lowest expenditures per person and does the lowest access to services and support here at RCEB. If that is the case, I'm wondering what the regional center is doing to amend that and get those communities up to parity.
- For myself, I think that services should be announced to the Asian families and community and there should be a huge emphasis placed on social and recreational services now that those have returned after I believe, like 12 years, and unfortunately, many families still don't have access to this. It is staying. It is unfortunate, but I hope that RCEB can continue to work hard to get those families to access the services and getting the information to families who speak Asian languages trying to keep door open to receive more input from the community it's always a good step. I hope this helps.
- DDS has given regional center funding to hire a diversity and equity specialist focusing on Asian communities. And we are so thankful to hear that because we have been talking about that for years, and I can you give us an update as to whether this staff is already on board? Or not?
- Yeah, I want to thank you. Lisa, and Jairo for your presentation.
- I received a form from SCDD, and I responded the survey for services in 2023-2024 back to them. This survey was sent out in English only. Will my answers affect my services?
- Lisa is going to retire in one year and we really appreciate her so much. She is going to retire from her position as Executive Director of RCEB and she has served at RCEB in different capacities. Thank you, Lisa for your services and for your dedication to the community.

Focus Groups

In addition to the nine Public Meetings, RCEB conducted 3 focus groups with families participating in Enhanced Case Management. Asian families were invited to the RCEB office to celebrate Lunar New Year and talk about POS Expenditures. Lunch was provided. The presentation to Latino families occurred during a regular support meeting.

I

Date: Friday, March 22, 2024, at 10:00 AM

Location: Regional Center of the East Bay
500 Davis Street, suite 100, San Leandro, CA 94577

Language: English with Cantonese and Mandarin translation

Number of Attendees: 9

Actions to improve attendance and participation: Forty families in enhanced caseload received invitation by mail.

Comments and questions from families

- My adult son has autism. He is looking for employment and needs help and support. We need job search and job coaching support.
- My child has safety issues and has difficulty communicating. He needs help with his behavior.
- My son needs one-on-one support to use social/recreational services. Can the Regional Center provide this type of support?
- My son is overwhelmed at work. What kind of support can the Regional Center provide?
- I'm a single mother with three children. One of them has autism. He was receiving services from the Regional Center, but the services were stopped. Michelle is helping me now to get the services restored.

II

Date: Monday, March 25, 2024, at 10:00 AM

Location: Regional Center of the East Bay
500 Davis Street, suite 100, San Leandro, CA 94577

Language: English Vietnamese translation

Number of Attendees: 38

Actions to improve attendance and participation: Forty families in enhanced caseload received invitation by mail.

Comments and questions from families

- I don't know who my Case Manager is.
- Do you have a psychologist to help my child?

- Do you provide mental health services to clients? It would be great if Regional Center provided mental health services.
- My son needs support with exercise and speech therapy.
- Can my son get YMCA services?
- My son cannot take care of himself and needs help with eating, going to the bathroom and we are getting older. How can the Regional Center support us?
- What will happen to our children when parents pass away?
- Does my lawyer (trustee) need to coordinate with the Regional Center?

III

Date: Thursday, March 28, 2024, at 11:00 AM

Location: 1870 Adobe St Concord Ca 94520

Language: Spanish

Number of Attendees: 9

Actions to improve attendance and participation: Forty families in enhanced caseload received invitation by mail.

Comments and questions from families

- My child is being bullied because he's diagnosed with autism.
- The reimbursement process is a barrier for families to access services.
- My husband's salary is an impediment for our son to use camping services.
- How many different programs can a consumer participate in?