

PUBLIC MEETINGS

I

Date: February 8, 2020 at 10 am

Location: Friends of Children with Special Needs
2190 Peralta Blvd. Fremont, CA 94536

Language: Presentation and Power Point in English. Translation into Cantonese/Mandarin

Number of Attendees: 15

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 from various Asian ethnicities. This meeting was combined with the New Lunar Year celebration.

Comments from attendees

- I want to know more about services and how to get them
- Eligibility (i.e. income, level of functioning) services available, coordination of services for school age child.
- My son was born in China and is applying for green card. If he gets services from regional center will it affect the application?
- Charnel is a great Case Manager. She always responds fast, is professional, patient, knowledgeable. She puts client in her heart
- Increase the pay rate of respite so more people would do it and less turn over
- Currently, I'm satisfied with services
- There's lack of transparency in both, visibility and understanding of the scope and variety of services available by RCEB. 90% of the services we have, we found out through families and not directly through RCEB. Need better understanding of how RCEB will take care of the child when/if parents are not available to act as guardians. How will RCEB take care as guardian/conservators? What is the process?

II

Date: February 10, 2020 at 9:30 am

Location: First Five Center
760 1st Street, Brentwood, CA 94513

Language: Presentation in Spanish – Power Point in Spanish

Number of Attendees: 13

Actions to improve attendance and participation: The meeting was held in collaboration with La Familia. Many participants are also members of a parent support group that meets regularly at this location.

Comments from attendees

- The RCEB webpage should be available in Spanish
- Who and how can assess my child's language needs? We need all information translated into Spanish
- We need Summer activities that develop our children's abilities. We need case managers to make at least 3 mandatory visits to the families to provide support to the families. The support group has served me well, very informative. Bring more information in Spanish. Provide more training, specifically for my daughter who's about to turn 18 or to receive information from the case manager. Provide more information and training to case managers who have been in the field for years so that they can better inform and support consumers
- My comment or concern is that there's no point in placing my child in a waiting list for adult services if there's no staff to work with them, maybe because of the low rates? By the same token, the caseload of service coordinators is too high and for that reason they don't inform parents about all services available, I also imagine their salary is not the best. In our case we need all information in Spanish.
- We would like you to help us by bringing "El Idioma The Wriglaw" to provide training with translation into Spanish for us, so that the Hispanic parents can learn about our children's rights in the school system and how to advocate for them. La Familia has been a good allied for us to learn about rights and survives for our children. We need help in obtaining childcare at home so that we don't have to send them out of home. I also ask that the RCEB webpage be translated into Spanish since we are the second largest population. We would like to have more meetings to learn about accessing services, ILS, Respite and the regional center.
- I want more information available about regional center services, as well as more classes about today's topic in Spanish and information in Spanish in the website.
- Personally, I would like more information for Spanish speaking families in Spanish. Bring more information to therapy centers so that parents can learn more about the regional center. I would like the information on the webpage to be in Spanish also since we are a large ethnic group and many of us do not speak or read English and this is a big barrier.
- My Case Manager (name provided) has not authorized respite/therapy at home for my children. I moved to this area 3 years ago. There's no information about services for our children since they were diagnosed with autism. Case Managers should by law, inform people with developmental disabilities about their rights. Information should be provided in our language. The schools are not helping children with autism to learn how to write. They should use iPad. The regional center should post information in other languages.
- The parent support group hosted by La Familia is important. We learn about all the existing benefits for our children. We need information in Spanish in the Regional Center's webpage
- In Contra Costa County we need more adult programs, the waiting list is very long. The parent training paid for by the Regional Center once a year should also be provided in Spanish, not in English only. Disability Rights California should have more staff to help our children, right now only one person speaks Spanish. Copies of Power Point

presentations should be provided in color, please. The public meetings hosted by the disparity specialist are very good specially because they are in Spanish, keep doing so. The disparity funds program led by La Familia has helped us a lot to understand how the regional center system works, the parent support group has helped us, I have learned about services provided by the regional center, please keep supporting them. Increase the rate for all people providing services to our children with special needs (respite, daycare, day programs ILS). The regional center webpage should also offer information in Spanish. We are the second largest population.

- We need these informational workshops to be in Spanish. They are very helpful. Thank you, very much
- The webpage should provide information in Spanish. It seems as if my Case Manager does not care about my daughter. She forgets the annual visit and other things.

III

Date: February 22, 2020 at 9:30 am

Location: Impact Hub Oakland, 2323 Broadway, Oakland, CA94612

Language: Presentation in English – Power Point in English

Number of Attendees: 25

Actions to improve attendance and participation: The meeting was held during the conference “Community Empowerment Project” hosted by Family Resource Navigators and Care Parent Network both service providers to RCEB consumers. The conference was held to empower the African American community through information and networking.

Comments and questions from attendees:

- Does the Regional Center help with housing and subsidy for low income families?
- I need potty training classes for children with autism
- What services are available for a 5-year old?
- Why is RCEB so inefficient with assisting families with getting services. The transition from Early Start to the school district is sometimes not smooth, many families got dropped with little contact from RCEB with School District transition
- African Americans may not use services because of embarrassment or lack of knowledge
- Equal access to services: I would like to see a database that sends/receives/creates alert based on child/young adult age group for events/info/opportunities that would benefit the family based on their demographic location and other information.
- You need to develop services for this group. There’s a need for programs for medically fragile/physically disabled adults. There’s nothing for employment and education and supportive living. My son has waited more than 4 years with no progress on services
- There are no day programs available for people with special health care needs to support their community involvement and activities. This includes social, educational and employment options. This problem needs to be addressed. My daughter has been on a waiting list for a day program for over 2 years

- There are no adult services for medically fragile young adults/adults. My son currently does not have any day programs or respite services because none exist for him. There should be services in the community that are accessible to adults with special health care needs
- How can I be on an advisory board to support your efforts and to support our children (African American specifically)
- It would help to have a binder/online, electronic binder with all information for all agencies and services for families to have updated every six months
- Legal support and victim assistance for special needs medically fragile clients. Support in the home
- No information provided about services or no response in months when email/call. Many services not provided in timely manner. Case worker stating “child not autistic enough for services”. As a case worker you get a glimpse of my life. I thought my case worker was a partner to help, instead I was not because of difficulties I face, she (case worker) attributed to life.
- My son was supposed to have his annual IPP in June. On that day I let them know that I would not be available because I would not be at home. I did this on purpose, just to see what would happen next. Up to this day I have not received an email or phone call from my case manager. I only received an email stating that she was going to be out of town and to contact her supervisor, should I have an urgent need. Last week I sent them an email reminding them that it was about time for my child to have his IPP, I also asked whether we had to wait until next year. I did this on purpose because I wanted to experienced personally how do they treat these cases. This type of situations affects the equal access to services.
- Case Managers need to be better informed about services offered by the center. Why not create a list of all services that parents need to know about from day one when your child is diagnosed?
- This was a very educational conference/session. Possibly a speaker about guardianship(conservatorship/POA/wills/life insurance/advance directives
- Having the resources come to all schools statewide (infant/preschool/k-12) and providing information to educators, families and communities about your services.
- Trying to get more hours for my son from regional center so that he can have someone come in from Manos and work for him to help with his walking but he needs more hours. They said that he gets the max which is 40 hours and that is not true and no one would work on 40 hours. I had someone but it wasn't enough hours for them. They had to come from Berkeley to Hayward.
- More programs for individuals with medical complexity or, for example cerebral palsy. 1) Afterschool care with their peers, not sitting at home alone 2) more regular short term away from home respite options (like for an extended weekend, etc.) 3)more options for programs after finishing transition, i.e. adult programs that are inclusive, not separated out by those that “more significantly disabled” vs. “more able” which causes segregation/isolation.

- I'm interested in learning more about the self-determination program. Please provide information about the monthly meetings held (local council committee meetings) at RCEB
- What legal support and advocacy can regional center provide? What are you doing about ABA shortage support?
- Our prior Case Manager had retired since past September 2019. We have not been contacted for the new Case Manager who will be taking my son's case. I will like to be contacted ASAP for Case Manager or supervisor. Also, been lack on follow up on my son's case. We haven't had an IPP in a very long time.
- Teena is amazing and always does a fabulous job. I have resubmitted an application for my daughter to be assessed for ASD and have not yet been contacted. This is my 3rd request

IV

Date: February 28 at 5:00 pm

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

Language: Presentation and Power Point English. Interpretation provided into 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 Asian ethnicities.

Comments from attendees

- We need help with transportation. We need more information
- We would like our child to get a bus pass every month to go to work from Monday through Friday
- I want my son to enter the program earlier. I don't want him to stay home too much, thank you for your consideration
- I need appropriate services and information. Need more time at school. I need more help for people with disabilities at home
- I need more information updated every month. I need to learn more about RCEB
- I need more hours at school. Also I need help with public transportation. I need RCEB to help with transportation and school

V

Date: February 29, 2020 at 1 pm

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

Language: Presentation in Spanish – Power Point in Spanish

Number of Attendees: 21

Actions to improve attendance and participation: The meeting held in collaboration with La Familia. The site is located in a neighborhood with large Spanish speaking population. Many participants are also members of a parent support group that meets regularly at this location.

Comments from attendees

- I need information about regional center services. My child is three-months old
- I want you to know that we have many problems with the agency Manos. Sometimes my social worker has to wait up to three months before she receives her salary for her work. I feel sorry that they are so irresponsible with this service
- I always have problems with my child's Case Managers. I always have to ask about benefits for my child, I have to call him
- How does receiving services free of charge for my child with autism will affect us. I have been told that we will have to pay back even if we qualify at the moment
- Why did 977 Spanish speaking individuals dis not receive services from the regional center? Why regional center adults living with relatives do not receive same financial benefits? I think there are not enough case managers for the community, their caseloads are so big that it's difficult for them to tend to the needs of their clients. I suggest to hire more case workers and to lower the number of cases so that they can provide support to the families.
- Sometimes it is difficult to find the right person to take care of our daughter or our children. Sometimes when we find the right person we cannot receive services from them because of their legal status. Sometimes, some parents do not request respite services either because there's not sufficient information or because of their culture where they are not used to receive services free of charge
- In our family it continues to be a challenge to find someone we trust to provide respite services. My daughter does not speak and I need someone I can trust to leave her without concern. Some people who could provide respite are not allowed because of their legal status. Still it would be much better to receive the service from those individuals than to receive the service from a total stranger sent by an agency. It would be ideal if people with ITIN # instead of SS # could provide respite services

VI

Date: March 3, 2020 at 10:00 am

Location: East Bay Services for the Developmentally Disabled
2141 California Street, Concord, CA 24520

Language: Presentation and Power Point Spanish.

Number of Attendees: 11

Actions to improve attendance and participation: The meeting was held in collaboration with Care Parent Network, and East Bay Services for the Developmentally Disabled, both service providers to RCEB consumers

Comments from attendees

- In my experience at the regional center I have noticed that what we need is that the Service Coordinators give us more information about programs to which we could qualify for according to our children's ages. Also, we should have more workshops in Spanish because we really lack knowledge of services available.
- We need more help for our children because we want to take some classes but we cannot access them
- My daughter just turned 3 and my case manager did not show up at the meeting I had at the school. I just learned that my child still qualifies for services at the regional center. The case manager did not attend my IEP
- Provide better training to Case Managers so they can help us better with services. We need more equipment for children with disabilities who cannot walk. Also, we need more information
- We need more people providing respite services because when I need the service for my son no one is available. I think the regional center should make sure that the service is available through agencies with enough staff.
- We need a directory that lists services. In this way we will know what types of services our children can have access to.
- Also, we need a directory of vendors accessible to parents so we can have timely information especially since not everyone knows how to access information through the internet.
- My son completed High School this year and I'm not ready for the next steps. I'm concerned about adult programs that are older than my son. He is 21 and I would like a program for individuals with same age
- My Case Manager offers me services but does not follow up. He says he will send paperwork by mail but the information never arrives

VII

Date: March 7, 2020 at 10:00 am

Location: Chinese Community United Methodist Church
321 8th Street, Oakland, CA 94607

Language: Presentation and Power Point in English. Translation into Cantonese/Mandarin

Number of Attendees:

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 Asian ethnicities. The site is centrally located in the heart of Chinatown.

Comments from attendees

- My sister was chosen for the Self-Determination program but I don't know who the Case Manager is and I don't know what we need to do
- I worry if the people I hire don't work, I will need to do the rest.

- My son was chosen for the Self-Determination program but it is very hard to hire people to help my son

VIII

ZOOM Instead

Date: July 15, 2020 at 1:00 pm

Location: ZOOM

Language: Presentation and Power Point in Spanish

Number of Attendees: 50

Actions to improve attendance and participation: The meeting was held in collaboration with La Familiar's Disparity Funds Program.

Comments from attendees

- I'm surprised with the data shared today. I would like to suggest that the regional center provide a list of services available for Latino families. Also, it would be a good idea that RCEB had a welcome letter along with an informatin guide for Latino families. We need a guide because they don't tell you what services are available and as a Latino parent one misses information about services and resources for our children. There's a home in Contra Costa that I would like for my daughter to live in, however the waiting list is so long that I believe that's another reason why we dont use services.
- Is there a guide that RCEB may provide where I can find services available for my daughter? She has autism and is 13 years-old. I would like to participate in the self-determination program and in the parent support group
- Mi daughter will turn 3 in September and she was expected to start receiving therapies when the school year started, however that will not be possible because of the shelter in place order. That means she wont be able to return to school, neither will she be able to have her therapies in person or to interact with other children. ¿What type of services can the Regional Center provide under these circumstances since my daughter is not going to attend kindergartden?
- What email should I use to inquire about whether my child was eligible to receive services at the regional center. Mi son is 5-years-old
- Is it possible to have our case from the regional center to La Familia?
- I feel that my Case managers have abandoned me and I think this has to do with the way Case Managers work. I think they should provide a guide with services available. Also, when we request a service there's already a waiting list. I would like Case Managers received better training about services so that they are better equipped to guide us.

- Would it be possible that RCEB had more interaction with cities and the activities they offer so that their activities and fields are adapted to the disability community so they feel included?
- My daughter is 17 years old and she just graduated from High School and plans to attend college. How can the regional center support us?
- Who can I call or how can I receive an application for regional center? When my child started school I was told my child would not be receiving services from the regional center because it was the School District obligation to provide the services.
- If a consumer 22 years old or older decides to rent his own room and live with his/her conservator, what benefits would he/she lose? Why do you think are the reasons for Hispanics not to use purchased services from regional center? What are the obstacles or the reasons?
- When my daughter was admitted into the regional center system I did not receive information about services that my child qualified for. For instance, I did not know about ABA or respite until I attended a parent support group.
- When Medical refuses to pay for a test that has been recommended by a doctor, would the regional center pay for it?
- Is there a services guide for my daughter who has autism?
- No hay vendors para out of home respite in west contra costa
- There are no vendors for out of home respite in west contra costa
- We need life skills services for adolescents, recreational services to promote social skills. A suggestion for RCEB: open ZOOM clases for consumers so they can socialize and be motivated.
- We need preparation for PCP before the program goes into effect in June 2021
- Lack of information is the cause for low POS by Hispanics
- It's good to have a plan for PCP. Also, some parents may not be able to attend some workshops because they are working
- Let's ask Lisa to help us prepare for PCP since it's around the corner
- Who provides the funds to pay for PCP for self-determination program before it starts in 2021?
- I want to clarify that we Hispanics are more attached to our children and even if a service is available one feels horrible to let your child go on his own. We Hispanics want our children to live with us for as long as they live otherwise we would feel guilty for abandoning them.
- What we need is that they be specific about services available so that we can see the ones that apply for our children.
- The parent support group for the self-determination program should be open for any parent since the program will be available for all in June 2021. In this way we could all be prepared
- My Case Manager told me that when my child starts school all services will be the responsibility of the school district not the regional center
- How can I apply for the self-determination program?

- What is the age limit to apply for regional center services?
- My child is 13 years-old and has never received all of the information about services available for him
- Thank you for the information to advocate for our children and use the services
- Thank you very much for your time and for planning this workshop with so much information.