



Date: January 27, 2020

To: Galen Dobbins, Legislative Aide
Office of Assemblymember Jim Frazier

From: Tonya D. Lindsey, Ph.D. & Sergio Iribe
California Research Bureau

Re: Results from the Assembly Select Committee on Intellectual and Developmental Disabilities
Digital Survey

You asked the California Research Bureau on June 20, 2019, to collate, summarize, and analyze data collected from “The Client Regional Center Survey” (survey) that your office made available online and at seven hearings of the Assembly Select Committee on Intellectual and Developmental Disabilities from October 2018 to December 2019.¹ Below are the California Research Bureau’s summary and analyses of the survey data. Please contact me at tonya.lindsey@library.ca.gov or 916-653-8667 if you have questions.

Introduction

The California Department of Developmental Services “oversees the coordination and delivery of services to more than 330,000 individuals who have cerebral palsy, intellectual disabilities, Down syndrome, autism, epilepsy and related conditions through a network” of **21** nonprofit regional centers.² The survey asked clients, caregivers and parents to rate their satisfaction levels on a scale of 1 to 10 with regional center services, delivery of those services, outcomes and their overall satisfaction with the center they use. The survey also included questions asking respondents to describe in their own words their experiences with regional centers. There was a total of 682 responses to the survey. Of those, only 235 respondents (34.5%) completed the full survey, and 408 (59.8%) addressed in their own words the question, “Would you like to share additional information regarding your interaction with the Regional Center?”

Because the survey results are based on a convenience sample--not a randomized representative sample--results cannot be generalized to represent all regional center clients, caregivers and parents. For example, there were no respondents who completed the survey representing San Gabriel/Pomona Regional Center. However, the results do represent the experiences and feelings of clients, caregivers

¹ The Assembly Select Committee on Intellectual and Development Disabilities staff placed the survey online and handed out the survey at hearings beginning in October 2018 at Fresno, Concord, Redding, Eureka, Coachella, and San Diego. <https://idd.assembly.ca.gov/informational-hearings> Data analyzed here represent a convenience sample of survey respondents who completed the digital or hard-copy survey through December 11, 2019.

² <https://www.dds.ca.gov/>, accessed on January 21, 2020.

and parents who did respond to the survey and serve to highlight issues for further inquiry.

We begin our summary with an overview of which regional center respondents said they used. After that, we offer a thematic analysis³ of the 408 responses to the question, “Would you like to share additional information regarding your interaction with the Regional Center?” Our analysis of the responses to that question identified regional center problems and solutions to those problems from the perspective of clients, caregivers and parents. Thematic analysis includes several rounds of coding, or identifying passages of text that are similar, where each round of coding generates more nuanced categories based on data. Initial thematic codes included positive, negative or mixed experiences. Refined codes included problems, solutions, praise, and general experiences. Themes that emerged during the analytic coding include topics such as general and specific services, staff, and funding and finances among others.⁴ Finally, we report how respondents rated their centers services and service provision.

Survey Respondents

The survey asked respondents (235) to identify their regional center. There was at least one respondent for every regional center except the San Gabriel / Pomona Regional Center (0).⁵

- Over half of the respondents reported using San Diego (32), Inland (30), Alta California (24), East Bay (23), and Valley Mountain (18) Regional Centers.⁶

³ For more information about thematic analyses, see for example, Castleberry, Ashley. 2018. “Thematic Analysis of Qualitative Research Data: Is It As Easy As It Sounds?” accessed October 3, 2019.

<https://www.sciencedirect.com/science/article/pii/S1877129717300606>

⁴ Axial coding is a method used to capture how codes are interrelated. For example, across problems, solutions, and praise are comments specifically about clients’ individualized program plans. And, within praise, focused coding revealed meeting goals and being treated like family as themes in the comments, for example.

⁵ As of November 2019, San Gabriel/Pomona Regional Center had a total caseload of 13,930; many potential respondents. https://www3.dds.ca.gov/FactsStats/Caseload_Main.cfm, accessed January 7, 2020.

⁶ As of November 2019, combined, these areas serve 133,324 people. Just 9.5 percent of those 133,324 people are represented in the survey either as a client, caregiver, or parent.

https://www3.dds.ca.gov/FactsStats/Caseload_Main.cfm, accessed January 7, 2020.

Department of Developmental Services
Regional Centers
(Colors correspond to areas served by each Regional Center)

Number of People Who Completed Survey by Regional Center
(n=235)

Name of Regional Center	n	%
San Diego Regional Center	32	13.62
Inland Regional Center	30	12.77
Alta California Regional Center	24	10.21
Regional Center of the East Bay	23	9.79
Valley Mountain Regional Center	18	7.66
Golden Gate Regional Center	15	6.38
San Andreas Regional Center	15	6.38
Redwood Coast Regional Center	12	5.11
North Los Angeles County Regional Center	9	3.83
Far Northern Regional Center	8	3.40
Kern Regional Center	7	2.98
Other (e.g., Multiple Centers)	7	2.98
Frank D. Lanterman Regional Center	6	2.55
South Central Los Angeles Regional Center	6	2.55
Central Valley Regional Center	4	1.70
Harbor Regional Center	4	1.70
North Bay Regional Center	4	1.70
Regional Center of Orange County	4	1.70
Westside Regional Center	3	1.28
Not a caretaker	2	0.85
Eastern Los Angeles Regional Center	1	0.43
Tri-Counties Regional Center	1	0.43
San Gabriel/Pomona Regional Center	0	0.00
Total	235	100.00



Updated: July 1, 2003

The thematic analysis revealed that many respondents described who they are in terms of their experiences as caregivers, sometimes to multiple children with special needs over many years:

As a single mom, this is put myself and my daughter In Harm's Way on multiple occasions. We have had over two dozen hospital visits in the last year.

Being the parent of a mentally challenged child who is now an adult has had rough times and good times.

I have one child in the regional center and it has been a terrible experience. I have another child waiting to be seen by the regional center since August 24, 2018

My daughter has been a client of GGRC for approx 36 years. I have been the parent/vendor for her supported living services for approx 20 years.

Positive Experiences with Regional Centers

In response to the question, "Would you like to share additional information regarding your interaction with the Regional Center?" 45 people shared positive comments and an additional 80 offered mixed reviews of their regional centers. Fourteen left responses that were not applicable. For instance, one client wrote N/A and another asked for someone to call them. The remaining 269 comments were

coded as complaints. We coded the positive and mixed comments about a regional center as praise. Positive comments reflect what respondents viewed as helpful about their experiences with a regional center.

Assessments, Diagnoses and Services

Clients, caregivers, and parents emphasized how important services and proper assessment and diagnosis are to their high satisfaction with a regional center. One parent recounted struggling to get a diagnosis for their daughter so she could access services. It was a regional center that finally made a difference after years of consulting with professionals who did not appear to help. Primarily concerned with their daughter receiving care after they can no longer provide it, this respondent said:⁷

My adult child, age 25, was just approved for services within the last month. It's been incredibly overwhelming for me struggling on my own for all these years, never having received an appropriate diagnosis from a medical doctor or therapist or school district. She had been diagnosed with several other disorders, since the age of nine (MDD, ADHD, OCD, and various anxiety disorders), so the ASD diagnosis really helps to understand her inability to function in life. I feel much better than I will now be getting help..... The people at Redwood Coast Regional Center have been great, especially considering the size of their client base and how hard they work and how dedicated they are. I'm getting old (age 65), so I really appreciate that she will be getting help, as I won't be there forever to help her. I should be meeting her caseworker in early February...

These experiences underscore the important role regional centers play in getting services approved after diagnosis.

Without RCEB our lives would be very different. RCEB provided my daughter with a diagnosis of autism when Children's would not, and recommended to us services...

Clients reported that living in an area rich with services as a positive; some people live further from services than others and would like services to be closer to them:

Not all regional centers are the same. We also live in a service-rich area. Not all areas offer the same amount of services (speech, ot, and ABA).

Still others are highly satisfied with finding or being guided to services, the availability of many different kinds of services, and accessing specific services:

The regional center has been crucial to me in helping me navigate the incredibly complex maze of services families need to access in California; I would have been lost without them.

⁷ All quotes from survey respondents are as they wrote them.

we are incredibly grateful for the services RC provides including a day program and supported living services.

My son is now 35 years old. He was assessed when he was 6 months old in Yolo county. Through two moves, to different counties, Alta and their staff have ensured my son consistent services without any lapse. They have listened to our needs, and his, and helped fulfill them all when able. Kudos to all who have helped my son.

My grandson has been a client for over 10 years. We have had help with IEP's almost every year. The regional has helped with respite workers, summer camps as well as Work training.

Thrilled to be in the self determination roll out!

Family and Teamwork

Some respondents reported that a positive regional center experience was not only supportive of clients but also of family members. Building close, family-like relationships with the people regional centers serve is appreciated by those who have those relationships. One person described staff as family.

They help me a lot they are part of my team

I consider those at the Derby House family. I do not know what I would have done without Inland Regional all these years

RCEB...recommended to us services that we needed so we could continue to be a two income family and enhanced my daughter's life.... It's fair to say I would not have been able to finish University and advance to my current professional position without RCEB.

Regional center does not just help. My child but helps me to. help. My child through its workshops and information on how to navigate IEP, get help for respite, access insurance services and other programs

We work closely with the regional center to make sure my son is receiving his supports and is living a dignified life.

Meeting Goals Through Guidance, Teamwork and Support

Clients and their families report being goal-oriented and appreciating when regional center staff help them reach their goals.

The Alta Regional Center has been very helpful to me and I am grateful that they helped me throughout the process to achieve many goals I can accomplish.

You support me with my self-control plan and I'm thankful.

Communication isn't always easy, but I've always had great guidance from the regional center.

Communication

Respondents acknowledged that their regional centers are changing and getting better at things they like regional centers to do such as listen, respond and share information.

Harbor has made significant improvements in client service and receptiveness to commentary over the last two years.

Only that they are doing a better job of telling people what is available instead of keeping it secret.

They are always very helpful and ready to answer any questions you might have and very friendly environment.

Suggested Changes from Respondents

Some of the 408 responses to the question, "Would you like to share additional information regarding your interaction with the Regional Center?" included suggestions for changes in regional centers' practices or policies:

Regional Centers Should Share Correct Information in a Timely, Consistent Manner

Some respondents indicated they are given incorrect information or alleged that some staff have purposely not given them the information they need. Some of these respondents and others suggested regional centers should provide lists or menus of services as well as support groups where other clients, caregivers and parents can share information and mentor or guide one another.

I also often hear the question, "What do you need?" but I don't know how to answer because I don't know what might meet his needs or what options are viable and available in my area. It feels like a question with no right answer - perhaps it would be better stated as a "multiple choice" question with options stated, instead of an open-ended, essay question with no data to work from.

They need to be more proactive in reaching out to clients and letting them know about new resources, and also in the follow up

I suggest that regional centers across the state form an alliance with hospitals to educate new parents of babies born with disabilities of their existence. This information should also be made available in new resident packages and in chambers of commerce. Communicate so no one is left out!

I would love to have information about services provided to ALL, and a consistent list of available services.

I wish the website were more up-to-date and more user-friendly.

There should be a universal document that can be provided so families know what is available and to who it is available.

Need for More Skilled, Knowledgeable Staff and Service Providers

Many of the respondents commented about high staff turnover and the frustration of having to start over every time they receive a new caseworker. Some commented that staff are underpaid, overworked, or in need of training. As a result, finding competent staff is a “hit and miss.” One respondent asked, “What is a caseworker?”

Since our caseworker has I believe over 100 clients, I would like GGRC to hire more case workers.

Some of the caseworkers are outstanding but they are often overloaded. Lightening their load by hiring case workers assistants might help.

There needs to be better supervision and training of the service providers who work weekly with the clients...but in all fairness I image they need to be paid better too.

Empathy training is needed at RCEB.

Services need the resources to pay the direct care staff higher wages so turnover is less

It is imperative that funding is increased for ALL vendors involved with the disability community. We should not have to beg, scrape, and wonder what more we could be doing for our special loved ones. Then there are families who get nothing because they are unaware of the existence and process of regional centers and their services.

Should be able to pay and get reimbursed if a provider is not a vendor. Should have more flexibility in how funds/budget is determined and used, and be able to administer funds with accountability without having to pay an independent administrator-that is an extra layer of bureaucracy and cost that could be eliminated.

DDS should raise the standards of training and rates of pay in order to create a stable, reliable and well trained workforce.

They need and deserve intensive and ongoing training, supervision and moral support to do a great job.

Payments and Funding, Generally, Are Cited as Problems

Some respondents reported not being reimbursed, while others suggested the overall system needs more funding or a complete overhaul. One respondent suggested eliminating regional centers and directly funding the children and adults who need services.

Regional centers shall be terminated and the funding shall be directly spent on the children who so desperately need help and support

I signed up to be a health care provider for my son last year in May and I've done all of the requirements and still have not received any money. Why is it taking soooo long?

It is not my impression that the regional center is the problem where there are issues, but that there isn't enough money in the system. Programs that closed after all the budget cuts have not been replaced, and there are just not enough openings for everyone who has needs

The rates of pay for my employees need to adjust with the cost of living. We do not need complex surveys or forms to fill out to justify the increases. We need to be able to pay our employees a wage that will keep them onboard and reduce the amount of staff turnover

The regional center services are hamstrung by the low wages paid for service workers. Without a pay raise, the vendors will disappear and no services will be available. It is vital to increase funding to remedy this crisis in care.

The law doesn't allow the regional center to pay it's vendors and providers out areas mandatory minimum wage

Mandated services are being denied by inadequately reimbursing vendors for services. Mom and pop vendors do not provide benefits (hire employees that are part time). The Governor says that employees that provide services to seniors need adequate pay and a career path-the dedicated staff that provide care to our family members need the same thing.

Bill for \$1500 for services that wasn't completed

Please help with giving IHSS and direct care givers at least \$15.00 per hour.. Her providers are desperately trying to find good staff but pay is too low to attract them..

Regional Centers and Service Providers Need Oversight and Should Be Transparent

Several respondents expressed a need for more oversight of their regional center and reported exerting great personal effort to make regional center staff follow laws such as the Frank D. Lanterman Act, which outlines the rights of individuals with developmental disabilities and their families:

I don't need someone to contact me on this I need IRC to be transparent, open up the lobby to those you serve, record meetings as you used to do and keep a dedicated email account for the board.

I would like to see additional family involvement and recognition of the important role that family caregivers provide to the clients being services by the Regional Centers.

Finally, the legislature should track how these organizations are closing the gap of employment disparity.

The Regional Center demonstrates a disregard for clients rights and the rule of law. They refuse to follow the Administrative Law Judge's ruling in my sister's fair hearing case. And there is little I can do about it. The RC abuses their power and is not accountable to anybody. It is time for reform. The CA legislature needs to amend the Lanterman Act and change the organizational structure of the regional centers and dispose of and replace the DDS. The regional centers should not have ever been private non-profits. These people are performing a government function yet because they are private not for profits, they answer to nobody but themselves.

Sadly, we are still fighting to have this group home shut down that abused our daughter and had 3 other clients die in less than 6 months....Our daughter lived in the home for two months and had 4 black eyes, yet has never prior or since ever has a black eye. She was being held down and restrained in her bed, locked in a back room with no ventilation being used off the garage during all the time she wasn't in her.... Yet, this home is still having clients referred and paid for by our state and regional center....it is clear that the way group homes are licensed, overseen, and ultimately given placements by regional center is very broken and is inadequate to keep our family members safe.

Access to Services Needs to Be Expanded

Some respondents asked for more respite care, financial, legal, transportation, emergency placements and services, employment, long-term care, and housing services. Many respondents reported being denied services they feel are needed, not knowing about services, or that they must travel some distance to receive services or get information.

They need more resources for higher functioning individuals

I think that the Regional Center should take a hard look at covering individuals with Fetal Alcohol Spectrum Disorders.

I would like to have meetings about services made available locally instead of travelling hours to attend special informational seminars. Those parents/caregivers who need help when we are no longer here to care for our special needs adults have difficulty getting sufficient information about services/housing that will be available to our loved ones down the road. I think that

seminars/informational meetings could be held locally, in our case at Exceed while our special needs person is attending workshops, etc. We could ask questions and not have to make special arrangements for travel for information on housing, etc.

There doesn't seem to be very many services in our area. VMRC really doesn't tell you what they offer and many times I have informed them of services. Also, there is not imagination when it comes to the services that are offered and seem to be a one size is supposed to fit all scenario. There need to be more options.

Also zero assistance / guidance with finances , how to not overdraw checking accounts, why not to take out credit cards or loans that don't have finances to repay, etc. Also, no advocates available outside of Alta Regional Center for when discrepancy is with Alta Regional Center and no advocates available when legal matters are involved.

There needs to be more services regarding employment and housing with our adult children.

If the state is going to move away from residential care for people with disabilities, there needs to be greater investment in local resources, especially in rural areas that already face difficulty in accessing services.

I hope that self-directed services are available to ALL Regional Center consumers very soon.

Social Skills should be offered to children with an ASD at ALL regional centers regardless of age or whether they have « finished » ABA.

I do think sex education for people with intellectual disabilities is critical, especially given that this population is 7 times more likely to suffer sexual abuse. The schools don't provide it, either.

Consideration for services for those who have safety concerns around water is important. ... Our kids desperately need swim lessons to help in case they fall in the water.

nobody at SDRC has ever sat down and asked, how many consumers need nursing care and aren't getting it?

Northern California has behaviorists that go with the individual to day program to help.

Concerns About Biased Award, Delivery of Services

Some respondents reported that “Hispanic,” “nonwhite,” and “non-English speaker” clients have a particularly tough time getting services.⁸

Please make a Spanish survey available to the community. Having only an English survey results in the lack of inclusion and promotes biased survey results. This is extremely important if you are really trying to hear what your community has to say.

Although things going well for my daughter with regional center I have been noticing that this is not true for lots of families. Especially Hispanics who constantly get denied and have to fight for services. If they don't have an advocate, they don't get what they need.

“Inland Regional Center has denied my child's right to services and denied my Hispanic community a right to be fully informed and educated. It has caused unnecessary delays and regression of my child's skills

As a community activist and advocate, it is also frustrating to see the lack of regional center support for the native Spanish speaking families in our communities. It is the belief of many that the regional center can and should focus on outreach to these disenfranchised groups. We, the community activists, have been responsible and instrumental in educating our local disability communities about their rights under the Lanterman Act, IDEA, programs available like IHSS and social security, not the regional centers. This really needs to change.

I feel it is incentive not to offer this in other languages. The disparity in the 21 regional centers are typically not white, non English speakers. 1 out of every 5 Americans speaks a different language. Yet their opinion isn't worth the time for you. Also, you scheduled a meeting on Good Friday in the Coachella Valley, canceled it then rescheduled it. I feel that the fact you are so out of touch with that community you would overlook Good Friday and Easter weekend leads me to think you have an alternative agenda.

Respondents' Overall Satisfaction with Their Regional Centers

The survey asked respondents (235), “On a scale of 1-10, with 10 being the highest, how satisfied are you with your Regional Center?”

- On average, respondents ranked their regional center at 6.5.
 - Of the regional centers with 5 or more respondents, Frank D. Lanterman received the highest average ranking of 8.8.

⁸ The California Senate Committee on Human services produced a report in March 2017 about addressing disparities in services provided by regional centers: https://shum.senate.ca.gov/sites/shum.senate.ca.gov/files/03-14-2017_heraing_background_paper_final.pdf

- Of those regional centers with 5 or more respondents, East Bay (\bar{x} =6.5), Golden Gate (\bar{x} =6.5), Far Northern (\bar{x} =6.3), Other (e.g., Multiple Centers) (\bar{x} =6.1), Inland (\bar{x} =5.3), North Los Angeles County (\bar{x} =4.8), San Andreas (\bar{x} =4.6), and South Central Los Angeles (\bar{x} =3.7) each ranked below the average ranking of 6.5.

Average Overall Satisfaction with Regional Centers (n=235)		
Name of Regional Centers	N	Mean
Frank D. Lanterman Regional Center	6	8.83
Kern Regional Center	7	8.71
Valley Mountain Regional Center	18	7.56
Redwood Coast Regional Center	12	7.50
San Diego Regional Center	32	7.38
Alta California Regional Center	24	6.58
Regional Center of the East Bay	23	6.48
Golden Gate Regional Center	15	6.47
Far Northern Regional Center	8	6.25
Other (e.g., Multiple Centers)	7	6.14
Inland Regional Center	30	5.27
North Los Angeles County Regional Center	9	4.78
San Andreas Regional Center	15	4.60
South Central Los Angeles Regional Center	6	3.67
Central Valley Regional Center	4	8.00
Harbor Regional Center	4	5.25
North Bay Regional Center	4	5.25
Regional Center of Orange County	4	4.00
Westside Regional Center	3	8.67
Not a caretaker	2	9.00
Eastern Los Angeles Regional Center	1	7.00
Tri-Counties Regional Center	1	9.00
San Gabriel/Pomona Regional Center	0	N/A
Overall	235	6.45

Respondents left comments exemplifying their satisfaction with regional centers in answer to the question, ““Would you like to share additional information regarding your interaction with the Regional Center?””

It's extremely upsetting, stressful, and depressing to be treated like this and I don't have any idea why. I am not aware of doing anything wrong or improper. By that I mean that I think I have behaved normally and no body has said otherwise. I'm afraid if I ask for help, it will just get worse.

Our family provided services for fourteen years. My son lived independently and had long-term employment (9 years). The SGPRC terminated family provided services. Soon thereafter my son was fired due to failed vendor services. My son was evicted and became homeless. My son was homeless for thirteen months while the SGPRC paid their vendor \$10,000 per month for services.

Feels like too much red tape.

They are absolutely worthless when it comes to being a resource.

When my son entered high school, I discontinued his services with Regional Center because they were not providing any useful services for him.

The interaction with the RC is difficult because their role has always seemed to be to minimize services offered rather than really try to coordinate a plan that will result in improvement.

Despite the reported necessity of fighting and advocating for services, some are also grateful they have regional centers and prioritize legal rights in their strategies to receive support:

We have been clients for over 21 years. After fighting to get in, we were grateful for the ABA services when my son was young.

I had to fight for my son throughout his life to receive support.

I've had to put forth alot of effort and fight for my son.

it makes me wanna just give up on them period. But my children have rights

As a parent, I am in constant learning and advocacy mode.

I do not ask for much and do get what I ask for even when we do not have a worker assigned.

Our daughter has always needed a lot of services. Unfortunately, we did not have the time to utilize them properly, by committing to the time it takes for therapy and following through on recommendations made by the service provider. We now have the time and commitment that it takes to provide the support that our daughter needs and IRC has been very helpful and understanding with their assistance.

Our son is in his 30s so we been with the regional center for many years. We finally have a case manager who is proactive and available to us if we need it. We have had to fight for services for our son In the past. RC is usually very fair. We are much better off living in California.

The reason I receive services for my two clients is because I educated myself in the Lanterman Act and the Welfare and Institutions Code. I will file appeals if I do not feel the denial for services

is with the guidelines of the Lanterman Act or the WIC. I go in to ask for services with the statutes in hand, and I generally get the services that I request. If not and it an entitlement covered by statute, I will file for an appeal.

I had to get a lawyer for them to listen to me. SARC and Service providers make promises they cannot, or have no intention to, keep.

Assessment Questions and Responses

The survey asked respondents (235) several questions about the regional center assessment process:

- "On a scale of 1-10, with 10 being the highest, how satisfied are you with the assessment process?"
- "How long did it take to schedule an appointment for the assessment of diagnosis?"
- "Did you receive an information guide about the services or resources offered by your Regional Center during the initial assessment?"
- "On a scale of 1-10, with 10 being the highest, how informed did you feel about the services available through the Regional Center following the initial assessment?"

On average, respondents ranked their satisfaction with the assessment process at 6.8.

- Of those regional centers with 5 or more survey respondents, Frank G. Lanterman received the highest average ranking at 9.8.
- Of those regional centers with 5 or more respondents, Alta California (\bar{x} =6.2), San Andreas (\bar{x} =6.1), Inland (\bar{x} =5.6), North Los Angeles County (5.6), and South Central Los Angeles (\bar{x} =3.5) each ranked below the average ranking of 6.8.

Average Satisfaction with Assessment Process by Name of Regional Center (n=235)		
Name of Regional Center	N	Mean
Frank D. Lanterman Regional Center	6	9.83
Kern Regional Center	7	8.71
Valley Mountain Regional Center	18	7.94
Other (e.g., Multiple Centers)	7	7.71
San Diego Regional Center	32	7.56
Redwood Coast Regional Center	12	7.42
Far Northern Regional Center	8	7.13
Regional Center of the East Bay	23	6.83
Golden Gate Regional Center	15	6.80
Alta California Regional Center	24	6.17
San Andreas Regional Center	15	6.13
Inland Regional Center	30	5.63
North Los Angeles County Regional Center	9	5.56
South Central Los Angeles Regional Center	6	3.50
Central Valley Regional Center	4	8.00
Harbor Regional Center	4	5.00
North Bay Regional Center	4	7.00
Regional Center of Orange County	4	4.75
Westside Regional Center	3	7.67
Not a caretaker	2	8.00
Eastern Los Angeles Regional Center	1	8.00
Tri-Counties Regional Center	1	9.00
San Gabriel/Pomona Regional Center	0	N/A
Overall	235	6.80

Respondents also reported it taking 1 to 2 weeks (28.1%), 3 to 4 weeks (28.9%), 5 to 6 weeks (16.6%), or longer (26.4%) to schedule an assessment of diagnosis.

Roughly half of the 235 respondents (52.3%) reported receiving an information guide about regional center services and resources during their initial assessment. On average, respondents ranked how informed they felt about services available through the regional center following the assessment process at just under 6.

For the question asking respondents if they wished to share additional information about their regional center, some respondents elaborated on how negative experiences with the assessment process impeded access to services, and a few stated they felt as if they were treated as less than human.

Also the assessment process was flawed. We had to apply two times and both times were denied so finally we appealed and had to point out every single thing that they already had in her

records. Then she was approved. She went for 5 years with no early intervention services because they have a flawed intake process.

then when we were contacted they wanted to meet with us IMMEDIATELY and expected me to take off work and pull my son out of school for an assessment, which I refused. I scheduled a time when my son and I could go in for an assessment, got to the Regional Center and no one seemed to know I was coming, then they found the psychologist that was suppose to assess him and she said she was not told that she needed to assess him! So she just observed him???

Our initial assessment was wrong by the psych at Regional Center and we had to document the original assessment of Autism by Children's Hospital and it was a three month process. He was in the foster care system at that time so services were desperately needed but took over 6 months to receive.

I don't know who is at fault for the delays, since there are so many parties involved. I know our first assessor blamed DCFS and DCFS blamed them, and then the service provider blamed everyone else, but it's just exhausting to navigate when connected systems aren't communicating properly.

It was the most frustrating dehumanizing process I've ever experienced. This was several years ago when my son was assessed.

During our initial assessment for our son (right around his 2nd birthday), we interacted with the most abrupt, uncompassionate psychologist.... After entering the room without even acknowledging us, she proceeded to sit with a clipboard watching our son for about 10 minutes. She then abruptly announced that yes, our son obviously had Autism. We were completely taken by surprise.... I began to cry and explain to her that no, our son couldn't possibly have Autism as he was so smart and advanced in so many areas. The psychologist looked at me, as I cried, and without any form of emotion or compassion said "tell me what makes you think he's so smart.".... I was so taken aback and shocked by her bluntness and total lack of compassion to our situation, I couldn't even formulate a response to her, and all I could do was cry..... we came to IRC believing our son had a simple speech delay, and we left with our world completely turned upside down and not a bit of empathy shown by the person who delivered the difficult news to us.

Individualized Program Plan (IPP) Questions and Responses

The survey asked respondents (235), "On a scale of 1 -10, with 10 being the highest, how satisfied are you with the IPP?"

- A majority of the 148 respondents (62.9%) reported having received an IPP.
- On average, respondents ranked their satisfaction with the IPPs at 6.5.

- Of those regional centers with 5 or more survey respondents, Frank G. Lanterman received the highest average ranking at 9.8.
- Of those regional centers with 5 or more survey respondents, North Los Angeles County (\bar{x} =5.7), Other (e.g., Multiple Centers) (\bar{x} =5.3), Inland (\bar{x} =5.0), San Andreas (\bar{x} =4.9), and South Central Los Angeles (\bar{x} =4.8) each ranked below the average of 6.5.

Average Satisfaction with Individual Program Plans by Name of Regional Center (n=235)		
Name of Regional Center	N	Mean
Frank D. Lanterman Regional Center	6	9.83
Kern Regional Center	7	9.29
San Diego Regional Center	32	7.53
Far Northern Regional Center	8	7.25
Valley Mountain Regional Center	18	7.11
Redwood Coast Regional Center	12	7.08
Regional Center of the East Bay	23	6.48
Golden Gate Regional Center	15	6.47
Alta California Regional Center	24	6.46
North Los Angeles County Regional Center	9	5.67
Other (e.g., Multiple Centers)	7	5.29
Inland Regional Center	30	5.03
San Andreas Regional Center	15	4.87
South Central Los Angeles Regional Center	6	4.83
Central Valley Regional Center	4	7.50
Harbor Regional Center	4	6.50
North Bay Regional Center	4	5.75
Regional Center of Orange County	4	4.00
Westside Regional Center	3	7.33
Not a caretaker	2	6.00
Eastern Los Angeles Regional Center	1	5.00
Tri-Counties Regional Center	1	7.00
San Gabriel/Pomona Regional Center	0	N/A
Overall	235	6.46

The survey also asked respondents “On a scale of 1-10, with 10 being the highest, are you, or is the individual you care for, improving/progressing with the IPP?”:

- On average, respondents ranked the improvement of the person with the IPP at 6.
 - Of those regional centers with 5 or more survey respondents, Frank G. Lanterman Regional Center received the highest average ranking at 10.0.

- Of those regional centers with 5 or more survey respondents, Far Northern (\bar{x} =5.6), Other (e.g., Multiple Centers) (\bar{x} =5.3), San Andreas (\bar{x} =4.5), Inland (\bar{x} =4.4), and South Central Los Angeles (\bar{x} =4.3) each ranked below the average of 6.2

Average Perceived Improvement Given Individualized Program Plan by Name of Regional Center (n=235)		
Name of Regional Center	N	Mean
Frank D. Lanterman Regional Center	6	10.00
Kern Regional Center	7	8.86
Valley Mountain Regional Center	18	7.56
Golden Gate Regional Center	15	7.20
San Diego Regional Center	32	7.16
Redwood Coast Regional Center	12	6.67
Alta California Regional Center	24	6.42
Regional Center of the East Bay	23	6.17
North Los Angeles County Regional Center	9	5.67
Far Northern Regional Center	8	5.63
Other (e.g., Multiple Centers)	7	5.29
San Andreas Regional Center	15	4.53
Inland Regional Center	30	4.40
South Central Los Angeles Regional Center	6	4.33
Central Valley Regional Center	4	7.25
Harbor Regional Center	4	6.00
North Bay Regional Center	4	4.50
Regional Center of Orange County	4	3.50
Westside Regional Center	3	7.33
Not a caretaker	2	7.00
Eastern Los Angeles Regional Center	1	6.00
Tri-Counties Regional Center	1	7.00
San Gabriel/Pomona Regional Center	0	N/A
Overall	235	6.23

Some respondents further elaborated on the IPP process when asked if they wished to share additional information about their regional center. Some people said they feel they have to watch the process closely to receive services even if those services are discussed in IPP meetings. And, to emphasize the general theme of good communication and collaboration with caregivers as a solution, one respondent described their caseworker as sensitive and as someone who listens to them during IPP meetings. They report that doing so helps to “address issues to improve individual’s potential.”

Why do I have to sign the IPP before the contract is written. I have ask and no Representative has been able to explain as of why, this inhibit the consumer from opposing what is written on the final IPP contract.

My biggest concern is that even after my worker sits with me and goes over the things on the IPP and there is almost always errors in it, information about my daughter that didn't get changed, etc.

Signed IPPs of my sons have been changed 2 times to wording in Alta's favor of not providing agreed upon services and upon my demand has been corrected, then agreed upon services get formally denied.

caseworkers and their supervisor spin the IPP process into a never ending stonewalling tactic, no person is present at IPP's that can make decisions on services.

ALTA Regional Center delays/denies providing services by running things through a staff committee at a later date when decisions should be made in a timely manner at the IPP meeting.

There was a face to face IPP meeting in early May 2018. Five months later, the written report came in the mail.

Case loads are too high. Processes are not explained. I still do not understand what services are available. often times it seems what we discuss in the IPP meeting and what gets translated to paper are not the same things. I have been told at two times Regional Center would help with therapy for my son, but it is never actually written in the IPP and he has yet to have any provided. We asked for ISP assistance months ago but have not even been contacted by an agency.

We moved here June 1 with a current IPP for 30 hours per week day program +30 hours per month working with a personal assistant to help my son with communication skills. Now, the end of October, in 5 months we have only received one month of services which consisted of only 7 hours discussing resumes and interviews.

My son was initially improving with the IPP when he had RC funded therapy services, 0-3. Now all he has is respite. He is improving but not as a result of the IPP since age 3. We pay out of pocket for tons of private therapy and special needs recreation classes to give him what he needs. We get no support on finding resources or funding them except for respite.

Denial of Services Questions and Responses

The survey asked respondents (n=235) "Have you been denied any services?"

- Over a third of the 235 respondents (37.5%) reported being denied services.⁹
 - Of those regional centers with 5 or more respondents, 82.6% of respondents with the Regional Center of the East Bay reported **not** being denied services.

⁹ Table not shown here.

- Of those regional centers with 5 or more survey respondents, 50% to over 80% of respondents with Inland, North Los Angeles County, Other (e.g., Multiple Centers), and South Central Los Angeles reported being denied services.

In answering the question about which service they had been denied, respondents reported the following services being denied:¹⁰ Behavioral management services, employment programs, home health supports, housing support services, independent living services, medical specialists and professionals, out-of-home respite services, pharmaceutical services, residential care homes, respite services–in-home, social/recreational services and non-medical therapies, specialized transportation, speech services, therapies (i.e., occupational music), and (added) funding/financial (e.g., co-pays).

Some respondents also added comments about services they would like to have but were not specifically listed as options to check off:¹¹

Pretty much everything but respite (and there are few competent, reliable providers to provide that)

LOL what services??? Almost all services to autistic kids under 18 have been cut.

Early Start/early intervention was erroneously denied. Needed advocacy to get eligibility

Inspection and evaluation of Intermediate Care Facilities in our area

help to make our home safe

Caseworker Questions and Responses

The survey asked respondents (235) several questions about their interactions with their caseworkers:

- “On a scale of 1-10, with 10 being the highest, how satisfied are you with your caseworker?”
- “How often do you speak with your caseworker?”
- “How long does it take to receive a response to inquiries made to your caseworker?”

On average, respondents ranked satisfaction with their caseworker at 6.7.

- Of those regional centers with 5 or more survey respondents, Frank G. Lanterman received the highest average ranking at 9.8.
- Of those regional centers with 5 or more survey respondents, Far Northern (\bar{x} =6.1), Redwood Coast (\bar{x} =5.9), Inland (\bar{x} =5.8), Other (e.g., Multiple Centers) (\bar{x} =5.6), North Los Angeles County (\bar{x} =5.3), South Central Los Angeles County (\bar{x} =4.8), and San Andreas (\bar{x} =4.8) each ranked below the average of 6.7.

¹⁰ Responses were coded according to service descriptions made available online from the Department of Developmental Services. https://www.dds.ca.gov/rc/docs/RC_ServicesDescriptions.pdf

¹¹ For a full list of respondents’ write-ins, see excel document “CompleteSurveyResponses_Analyses_TLindsey_TDL_20190703.”

Average Satisfaction with Caseworker by Name of Regional Center (n=235)		
Name of Regional Center	N	Mean
Frank D. Lanterman Regional Center	6	9.83
San Diego Regional Center	32	7.97
Valley Mountain Regional Center	18	7.72
Golden Gate Regional Center	15	7.47
Regional Center of the East Bay	23	6.96
Kern Regional Center	7	6.86
Alta California Regional Center	24	6.83
Far Northern Regional Center	8	6.13
Redwood Coast Regional Center	12	5.92
Inland Regional Center	30	5.77
Other (e.g., Multiple Centers)	7	5.57
North Los Angeles County Regional Center	9	5.33
South Central Los Angeles Regional Center	6	4.83
San Andreas Regional Center	15	4.80
Central Valley Regional Center	4	9.75
Harbor Regional Center	4	6.75
North Bay Regional Center	4	6.25
Regional Center of Orange County	4	4.75
Westside Regional Center	3	6.33
Not a caretaker	2	8.00
Eastern Los Angeles Regional Center	1	8.00
Tri-Counties Regional Center	1	10.00
San Gabriel/Pomona Regional Center	0	N/A
Overall	235	6.73

- Respondents reported speaking to their caseworkers annually (57.0%), bi-monthly (22.1%), monthly (15.3%), or weekly (5.5%).
- Some respondents (18.3%) reported it taking longer than two weeks to receive a response to inquiries made to their caseworkers.
- Of those regional centers with 5 or more survey respondents, 42.9% of Other (Multiple Centers) respondents reported it took longer than two weeks to receive a response to inquiries made to their caseworkers. Over a third of respondents from Far Northern, Valley Mountain, Redwood, North Los Angeles, and South Central Los Angeles regional centers reported it taking longer than two weeks for their caseworkers to respond.

Some answers to the question, “Would you like to share additional information regarding your interaction with the Regional Center?” were comments about problems with caseworkers. Generally, many respondents reported that high caseloads and overwork may lend themselves to high turnover and a lack of knowledge and relationship-building with clients and families. They suggest that

caseworkers withhold information about services and treat client poorly as if they want something for nothing. Some described caseworkers as gatekeepers who dissuade them from asking for services. The first two comments below touch on several common themes:

The caseworkers are obviously overloaded, do not know what services are offered, often change and are often inexperienced and don't know their clients or families very well. Our family's experience has been widely variable. Some case workers we've had never respond to phone calls or e-mails, many routinely say services that should be provided according to the Lanterman Act are not available.

Case workers are overworked, turn over regularly, and have no one to help triage/monitor client needs and circumstances, and are rarely proactive at suggesting services to clients from which they might benefit.

I have been a part of regional centers for the about 18 years, the last 14 have been with San Diego Regional Center. I have had good and really bad case workers. At one point I believe I had 4 case workers assigned in under a year. I feel every time I get a new one that I often know more about what they should be doing than they do. There was a point where I couldn't contact her case worker because she had left and nobody informed me,

It seems that case workers are told not to inform families of all the possible services. And she. You learn of services and ask your case worker it is latterly met with denial or a fight.

I have had to file complaints about my sons regional center case mgr because she is ridiculously hard to get ahold of. She does not advocate for my son. I have had to research my sons rights and advocate for him myself.

RCEB has a culture where case managers view clients with suspicion and treat us like we want something for nothing and that clients and their families always have their hands out.

I think Regional Center staff are doing the best they can with what they have. They cannot truly advocate for and case manage as I think they would like with their current caseload ratios

Service Provider Questions and Responses

The survey asked respondents (n=235) several questions about their experience with service providers:

- "On a scale of 1-10, with 10 being the highest, how satisfied are you with your service provider(s)?"
- "Are you currently on a wait list for services," and "If so, for how long?"

On average, respondents ranked their satisfaction with service providers at 6.7.

- Of those regional centers with 5 or more survey respondents, Frank G. Lanterman received the highest average ranking at 9.8.

- Of those regional centers with 5 or more survey respondents, East Bay (\bar{x} =6.4), Other (e.g., Multiple Centers) (\bar{x} =5.9), Inland (\bar{x} =5.5), Far Northern (\bar{x} =5.5), San Andreas (\bar{x} =5.3), and South Central Los Angeles County (\bar{x} =4.5) each ranked below the average of 6.7.

Average Satisfaction with Service Providers by Name of Regional Center (n=235)		
Name of Regional Center	N	Mean
Frank D. Lanterman Regional Center	6	9.83
Kern Regional Center	7	8.71
Valley Mountain Regional Center	18	7.61
Golden Gate Regional Center	15	7.47
San Diego Regional Center	32	7.38
Alta California Regional Center	24	7.00
Redwood Coast Regional Center	12	6.92
North Los Angeles County Regional Center	9	6.89
Regional Center of the East Bay	23	6.43
Other (e.g., Multiple Centers)	7	5.86
Inland Regional Center	30	5.53
Far Northern Regional Center	8	5.50
San Andreas Regional Center	15	5.27
South Central Los Angeles Regional Center	6	4.50
Central Valley Regional Center	4	7.00
Harbor Regional Center	4	7.50
North Bay Regional Center	4	6.75
Regional Center of Orange County	4	3.50
Westside Regional Center	3	8.67
Not a caretaker	2	8.50
Eastern Los Angeles Regional Center	1	8.00
Tri-Counties Regional Center	1	9.00
San Gabriel/Pomona	0	N/A
Overall	235	6.73

When asked whether or not they are currently on a waitlist for services, 17.9% of the 235 respondents said yes. In order of frequency, of those who responded to a write-in question about how long they had been waiting for services (55), most did not report a quantifiable time (69.3%) followed by those who reported waiting for less than 6 months (16.4%), 6 months to 1 year (12.7%), over 1 year to 2 years (10.9%), and longer than 2 years (10.9%).

For those not writing in a length of time, comments included:

What services? Except respite there are none for autistic kids under 18.

Not sure of time currently waiting for group home openings

It's not a wait list. There is an acute lack of ILS/SLS opportunities because rates are too low for our area.

Not on any wait list..... just been waiting for Community-based program

RC don't have "wait list"

nothing was offered- just a denial

due to inadequate reimbursement our agency Aldea Family Services is dropping its Supported Living Services Program there was onl

It's not a wait list. There is an acute lack of ILS/SLS opportunities because rates are too low for our area.

I'm still waiting for the appointment that never was scheduled correctly