Independent Evaluation of the Service Access and Equity Program

California Department of Developmental Services

Appendices

Submitted by Georgetown University National Center for Cultural Competence

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APPENDICES

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Appendix A
Qualitative Coding Tables: Regional Center Director Interviews

Qualitative Coding Tables: Regional Center Directors Interviews

Listed below are the coding structure and illustrative comments that emerged across all the structured interviews convened with the Regional Center (RC) Directors (n=18). Table 1 and Figure 1 provide the number of years participants served as an RC Director. Tables 2-21 presentthe coding structure with frequencies and selected delineative quotes.

Table 1. Years in role/current position

Years as an RC Director	Frequency
Less than 1 year	2
1-4 years	5
5-9 years	7
10 – 19 years	1
20+ years	3

Figure 1. Self-reported number of years served as a regional center director
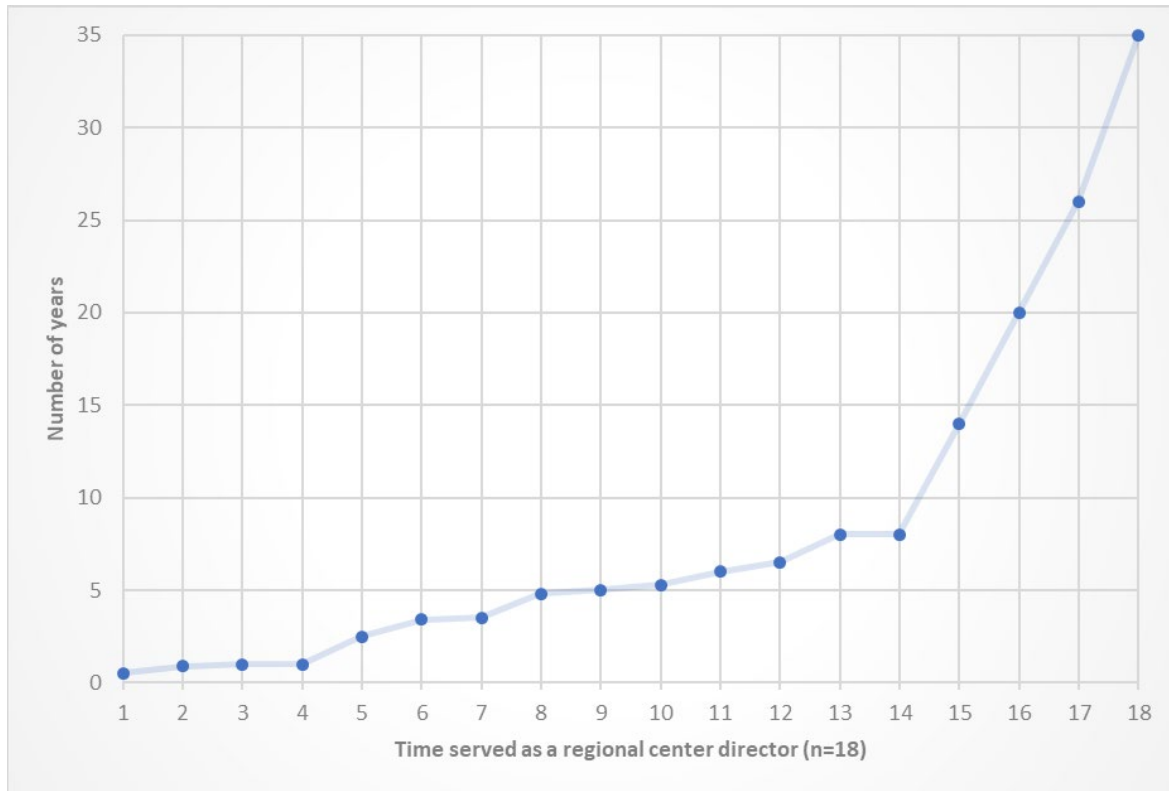
Table 2. RC Directors' responses to the racial, ethnic, and linguistic disparities among people with intellectual and developmental disabilities (IDD) in their region

Coding Structure	Frequency	Illustrative Quotes
Disparities due to geographic location	4	"Sometimes distance to accessing services can be an impediment. If a service, for example, is not locally available, then the person or their family may need to travel to receive the services, which can be a barrier." "Within that rural area, there's a long drive in order to reach those populations. Many Latinos who are working, they're working during those standard hours that we, as a regional center, need to adjust to their schedules."
Disparities due to age	3	"For us, in our area, the largest differences in per-capita expenditures -- because that's the focus of the POS data that we get from the state -- is in adults. Both as far as the disparities having to do with ethnicity and the disparities having to do with language. They're really amongst the adult group. In our system, adults are identified as those individuals that are 22 and older. That's where we see the biggest disparity, not so much for the zero to three years group, the early start folks, and not so much for the ages 3 to 21. That's where the largest disparities lie for us. Then, we've met with our communities' countless times over the years on these issues. Some of the things that we've learned from the community that we think impact those disparities for adult groups would be cultural preferences."
Difficult to ascertain due to lack of data and analysis	3	"I don't know if anyone in the state can answer that question in a competent analysis of data that is meaningful. I think that, obviously, the theme of insufficient data that doesn't give us information to take action is one that I care about because that is somewhat problematic. More than somewhat. It is problematic."
Disparities in Purchase of Services (POS) and access of services	3	"When you look at purchase of service dollars both in a lump sum annually as well as by per capita, you see differences in what different folks in ethnic and language, and racial groups have spent on them." "In terms of disparities, what we see in our catchment is that individuals from...We see disparities in a few different areas. Some of it's by ethnicity. We see that individuals from diverse communities are accessing services at a lower rate than individuals from the White community."

Table 2 (continued). RC Directors' responses to the racial, ethnic, and linguistic disparities among people with intellectual and developmental disabilities (IDD) in their region

Coding Structure	Frequency	Illustrative Quotes
Disparities due to cultural preferences in types of services utilized	2	"The living arrangements for the white and Hispanic individuals are such that some of the Hispanic families, because of their cultural preferences, don't want to place their loved ones outside of the home. I think that that has a huge impact as far as seeing some of those differences between the white folks and the Hispanic families."

Table 3. RC Directors' responses to the root causes or factors that contribute to disparities in California's system for persons with intellectual and developmental disabilities (IDD) and their family members from racially, ethnically, culturally and linguistically diverse groups

Coding Structure	Frequency	Illustrative Quotes
Complex systems of supports and services which are difficult to navigate and understand	9	"It's complex for the people who work in it, it's particularly complex for those individuals and families trying to figure out how to access and use our services, or to even know about our services, in spite of all the outreach that we do." "Not only do people have to navigate the regional center system, they also have to navigate every other system first, school district, department of mental health, department of rehab, government agencies…" "We're a complex system. Nothing else like it, with a lot of technical terms within the regional center system. I've been here for a number of years, and I'm still learning acronyms. I'm still learning services and supports, even in my role. Trying to communicate that to individuals in a way that is family friendly has been an issue."
Irrelevance of the Lanterman Act supports and services to community needs	5	"The supports that families were looking for are not reflective of today's familial values of our community. Back in the late '60s, if you couldn't support your loved one in your home, they went into an institution. There was out-of-home placement. Today's environment, for our Regional Center at least, is very much, "What can I do to keep my family member at home?" "I think that when the Lanterman Act was developed, it was developed by predominantly White, middle-income families. We fast-forward to today…White middle-income isn't our norm for my community." "The root cause is the Lanterman Act. It is designed to meet the individual needs of people. It was never designed to be like Medicare. You're eligible, and everybody gets A, B, C, and D. The program is meant to meet where the person is at a given point in time, and not on a diagnosis of autism across the spectrum, for example, or down syndrome. The root cause is the very system that is there to protect the people, because it's never changed."

Table 3 (continued). RC Directors' responses to the root causes or factors that contribute to disparities in California's system for persons with intellectual and developmental disabilities (IDD) and their family members from racially, ethnically, culturally and linguistically diverse groups

Coding Structure	Frequency	Illustrative Quotes
Large case loads	4	"Having caseloads at 95 and 100 when they're statutorily supposed to be at 62 and 66 is a direct connection, and a root cause of disparities. I've sat with our bilingual/bicultural social workers who talk about the days when they used to be able to have enough time to go to an IEP, and support the family in battling with the schools to get what they are entitled to from special education. You can do that at 60 if you're serving 60 people. If you're serving 100 people, you cannot do that because there's too many crises going on." "High caseloads, let's start there. When service coordinators have caseloads that are exceedingly high, it limits the amount of time they have to spend with families, to connect them, not only to regional center services. That's the easier part."
Lack of racial, cultural, and ethnic, concordance of service providers and recipients	4	"The number of employees service providers need that have these other language abilities, these other cultural understandings...I don't think we can put a number on it. I don't think we really know, but we're always looking. Our families are always saying, "When are you going to find more Korean OTs [occupational therapists]? When are you going to find more Russian PTs? [physical therapists]"? When you have monolingual families, and those professions that I just mentioned, if you go into the universities, you're going to find Caucasian. You'll probably find Latinos. Whether you find a lot of other languages, because they're not recruiting, because they don't know that there's this problem." "We've got very historically older generational providers that did not have that lens when establishing how that delivery of service would look like. It's bringing those traditional providers to be able to deliver a service then can meet the needs of these communities. That comes down to that cultural competency. During that [our project process] is to understand who that population is. As an agency, maybe just not within the regional center but our outside vendors, that they also need to grow to be able to establish and address what cultures they may need to be serving. Many times these agencies aren't growing with the demands of the population."

Table 3 (continued). RC Directors' responses to the root causes or factors that contribute to disparities in California's system for persons with intellectual and developmental disabilities (IDD) and their family members from racially, ethnically, culturally and linguistically diverse groups

Coding Structure	Frequency	Illustrative Quotes
Lack of trust in authority and government	2	"We did have a lot of trust issues, as well. During that one era, the certain time of the world where it was looking at Hispanic people, looking at ICE things that were being said in the media, politicians who would say disparaging things. Why would you let a social worker come into your house and do these things? They could be turning you in, or doing some things that are going to hurt your family and not help your family."
Lack of resources and disparity in funding	2	"Well, something that I say in subtler ways to legislators and their staff, you get what you pay for. You underfund the system since 2008, 2009. I get 50 percent of what it costs to staff a regional center. These are some of the unintended consequences of those draconian cuts. There's been some investments recently. We're going to hire additional staff, but it doesn't fix the core staffing issue. Until that's fixed, those root causes are going to continue."
Personal circumstances	2	"Additional disparities are involved with educational levels, that many families have low literacy levels so it makes it hard for them to advocate for the client with intellectual developmental disabilities, leading to many not becoming eligible later in life … With that limited language, and education, and getting their needs met, and then advocating for their family members and trying to honestly navigate through a system that's set up more on, again, standard working hours, 8:00 to 5:00. It's looking at not being able to access to that level."

Table 4. RC Directors' responses to the current status of disparities in Purchase of Services among the racial, ethnic, and linguistically diverse populations supported by their Regional Center

Coding Structure	Frequency	Illustrative Quotes
Evident racial disparities in POS expenditure	4	"It's very visible that individuals who are white receive more money from the regional center. It's in the data. It shows. If I'm at community meetings, I highlight that. I talk about it. I own it. I'm not proud of it, but I own it, because the data is there. That is very visible."
Evident disparities in adult and transition services (In comparison to early start services)	3	"What I see is I see a lot less disparity, if any disparity, with our early start program. Then, there's a lot less POS expenditure during the school years. Then, when you get into the adults out of school, 22 and up, there's more disparity there."
Need for a deeper understanding of cultural and linguistic diversity in communities	3	"If you look at Latinx communities, it's disrespectful to equate Salvadoran culture with Mexican culture, Argentinian culture, Costa Rican culture, with Spain's culture. Those are all dumped into this category of brown skin people. That doesn't make any sense to me. Similarly, Asian communities…We have to get more sophisticated not only on the regional center service side of understanding the disparities but also on the ethnic categories."
Evident ethnic, cultural and linguistic barriers	3	"We have the monolingual individuals and families, especially from the Hmong. We have a huge Spanish population here, which is 55% of our population we serve, they are from a Hispanic background. It's not necessarily that they don't speak English, they do speak English, most of them, but they have from that culture and background and Hmong we have a huge Hmong community here in the central valley, and those are the two groups that we need to tackle."

Table 5. RC Directors' responses to why their Regional Center decided to submit a proposal to DDS for its Service Access and Equity program

Coding Structure	Frequency	Illustrative Quotes
To improve language access	7	"One of the weaknesses that we had as we interviewed our community, was not having our material well translated. A big focus was making sure that we had our access points as easy to understand as possible. We broke it down to the simplest terms, so that people would be able to get and understand what we were, who we were, how we could help." "Well, in the beginning, it was to ensure we had the information out in languages that were easy to understand. That our website was easy to navigate, and that we had the support to continue doing a lot of our outreach that we were doing." "One is assisting the monolingual Hmong speaking families to understand the regional center, the health care system, the education system, the terminology…kind of close the gap to get the terminology and the barriers out of the way to make sure everybody understands what they're receiving."
To conduct outreach to underserved communities	6	"The reason that we did that was because we realized, recognized that our Native American population was not accessing our services. We knew through our connections that there were children and individuals on the reservation there that needed our services, but that there was an issue of trust...gaining trust of their community, so that they would reach out to us and access services. That was our focus. We hired a person who lived on the reservation up there, the [name of reservation] and she still works for us. That was our focus then was to try to get up our numbers of referrals there, and access to services." "The idea was if folks have a better understanding of the services that are available to them then that would help with access to those services. It would allow our service coordination staff to better assist those families that have experienced disparities in the system."

Table 5 (continued). RC Directors' responses to why their Regional Center decided to submit a proposal to DDS for its Service Access and Equity program

Coding Structure	Frequency	Illustrative Quotes
To address family and community needs in a culturally and linguistically competent manner	4	"I think it's at the core of what we need to be doing as an agency. If you want to talk about being person-centered, you can't be person-centered unless you take people's cultural and linguistic needs into account. When I got here five years ago, I heard loud and clear from our Spanish-speaking community that they did not feel welcome here. They felt discriminated against. They didn't feel heard. They didn't feel like this regional center was making an effort to connect with them in any kind of meaningful way. I felt, and still feel, that must be a priority, and so did our board." "We were getting feedback from the community that we needed a model that would allow for a parent and family perspective to help troubleshoot issues outside of the regional center. If there were issues with trust, that this might be a person people could relate to."
Educating and training and interpreters to better serve families	2	"The thing with the interpreters, getting them to understand because they're going to take it and give it in another language, so they need to get it and understand it deeper. I think everything that we've been doing in those particular years that you're talking about had to do with understanding a deeper meaning in a deeper way their system, their community."
Sub question: Is this project expanding capacity or is it new work?		
Expanding capacity	7	"I would say it was definitely expanding our capacity. About 60 percent of our service coordinators are bilingual and bicultural. I would definitely say that it was expanding it in a formalized fashion."
Creating new work	3	"It was something that we didn't have before, so it was specifically a creation of that grant itself."
Both	3	"The ones we've done have been used for both."

Table 6. RC Directors' responses to their Regional Center's definition of equity for persons with IDD and their families

Coding Structure	Frequency	Illustrative Quotes
Services and supports allocated and provided based on needs	9	"To me, equity would be recognizing that not everybody is starting from the same place. People may need different supports and services to have the same opportunities as their peers." "I think it gets complicated to say, 'Spend the same amount of dollars on everyone.' It's better to say, 'How do you outreach into underserved communities to make sure that they have all they need in understanding and tools to be able to access the services.'" "Just because someone who's Hispanic/Latino utilizes $10,000 a year, and somebody who's White utilizes $20,000 doesn't mean there's inequity. I think that the true measure of it is, are the needs being met? Are the needs related to the developmental disability being met? Is that community, the Hispanic/Latino community, as aware and knowledgeable about our services as our white community is? That's a big thing. Once they do become aware, are they able to understand our system in the same way?"
Equal access to information, resources, and opportunities	7	"For us, we define equity as equal access…equal access to both the regional center support and equal access to the services from our service provider community." "Equity, we look at is that everybody has the same access or opportunities to those resources. The ones we try to utilize is that we have information available in all languages, that we explain things in a consistent manner, that we offer and explain things in the same type of way, as much as we can, from that perspective." "Equity really is making sure everybody gets the same amount of information for them to make an informed decision on the next steps."
No explicit definition	2	"To be honest, I don't know that there is one overarching definition of it."

Table 7. RC Directors' responses to the levels their project was designed to mitigate disparities

Coding Structure	Frequency	Illustrative Quotes
Individual	16	"It included things like teaching each person not only about the regional center and what services we provided and making information they needed more accessible to them, but also teaching them things like person-centered planning. It was about how, as an individual or as a family, to really work with the planning team, identifying the individual's strengths, needs, goals, all of that stuff to be person-centered. Thereby having a better assessment of needs and a better way to decide which resources would best meet those needs."
Community	14	"We've completely changed our connection to the community in general…we did 180 different events in our community, where we generated information about different parts of what we do as a regional center, in English and Spanish. Then, we just went out and participated in every kind of cultural event that was going on throughout our region." "The community level is the peer connections and creating the leaderships. Those leaders will then connect with other agencies. We can also see when there are the connections within those other agencies then the referrals can also happen. They know that there's an existing service to address the needs."
Family	13	"We did take a holistic approach. Certainly, who's registered with us is the consumer, but the family has to be doing well, particularly Mom, Dad. What do they need in their lives in order to be able to care for their son and daughter? It is a holistic approach that we look at."
Organizational	8	"Yes, because a lot of the information that we structured here was with the input of our staff, and then we use that information to train our staff now so that when they're working with families, "Here is your reference point, and we want to make sure that you understand it." "We don't see it as a grant program that's separate from the rest of the organization. We started and we've continued to educate our entire staff about what we're doing to bring folks into the system and to be supportive. We've changed our purchase of service policies as well, based on certain experiences that we have had."

Table 7 (continued). RC Directors' responses to the levels their project was designed to mitigate disparities

Coding Structure	Frequency	Illustrative Quotes
Systems	7	"At [our regional center], we did try to bring awareness through this grant money about what was working and what wasn't working for the individuals that we serve and also for their families. We did share the project outcomes and the activities with our staff." "Again, educating our partners out there in the community. Head Start programs, we're working with them. We're working with the Department of Children & Family Services, educating them about what our needs are… We've had special meetings with the health systems, in terms of doctors and in terms of how they interact with our families and giving them tips on what we see, etc. Anytime we have an opportunity to do that kind of thing, we're doing that."

Table 8. RC Directors' responses to culturally competent approaches used to implement the grant, specifically in supports, services, and project activities

Coding Structure	Frequency	Illustrative Quotes
Culturally representative staff	4	"We have a department, a team that's been put in place to address these particular issues on community outreach. The individuals that are lead staff, who are participating in the writing, [and] participating in the planning, are individuals that reflect the communities served, which I think is critical."
Creating avenues to identify and listen to families' needs in a culturally competent manner	3	"Absolutely, yes. I would say again, going back to the Promotora project, when we first were working with the agency that actually has the contract, they helped us develop. They brought to us a curriculum but they also helped us develop pre and post-tests, kind of a self-assessment tool. Families would assess their ability of their knowledge at the regional center and whatnot. Then they would do that pre and post, because, of course, we're hoping that their knowledge has improved. They also helped us develop a tool for families to use to identify what goals they wanted to accomplish in their year with the Promotora."
Seeking to expand knowledge on cultural humility and competence, and seeking guidance and consultants	2	"We're doing *Partners in Policymaking* right now. We've done so much into building that up. That was done very intentionally with a cultural lens, with a culturally competent lens. We had a project we did with [an organization]. That one was two years. It was just before the pandemic, and then the pandemic hit. We went in full stride. I think we probably worked six months or so with them before we went into the pandemic.
Not sure	2	"I don't know that our plan focused or had a culturally competent component specific to it…as part of our diversity, equity, and inclusion initiative...we are doing cultural proficiency. There's so many. That's competency, proficiency, sensitivity, humility. It's so interesting, the debate that goes on about, is there truly such a thing as cultural competence? It's really more about humility and sensitivity or ongoing learning."

Table 9. RC Directors' responses to linguistically competent approaches used to implement the grant, specifically in supports, services, and project activities

Coding Structure	Frequency	Illustrative Quotes
Translation and interpretation of materials and resources	10	"They have translation available from all of our core languages. From the linguistic perspective for being able to communicate, and even in our writings, we have a communication strategy that includes our five threshold languages for here." "We do that, and then we've been developing our interpreters and our translators. We've got more than we've ever had before. Now, it's just a normal course of work for us in the regional center, is to get them to whatever document that they need or even ask for, that we get them into their language." "Some of the meetings were held in Spanish because that's what the community requested. We had Spanish speaking facilitators and trainers available at those gatherings. I think that those were some of the approaches that helped us."
Linguistically representative staff	5	"We have always provided the differential for Spanish speaking staff, and Spanish speaking staff within our provider agency, and contracted with interpreters on the phone at any given moment."
No	3	"I didn't put a lot of emphasis on the linguistic. It was more on the cultural and bringing on that kind of support."

Table 10. RC Directors' responses to whether or not a theory of change framework was used for their grant project

Coding Structure	Frequency	Illustrative Quotes
Don't know	6	"That might be an area that I don't know if it's specifically spelled out. Even though the activities, the ones that I've written, are the activities get us there, I would have to take a look to see what they did here."
No	4	"I don't think we did specifically, no."
Not formally	4	"We did not necessarily use theory-of-change specific language…To the extent the [grant] questions allowed for us to do that, that was a focus as far as what we were proposing to do, what we anticipated as change, why it would be important to do that. In this case we were able to draw a correlation between previous [project] that we had done and the feedback that we had heard."
Yes	2	"We did. I'm trying to remember which. I don't want to cheat and give you the wrong years because we were much more intentional in our last two than we were in the past. All the things that we learned at [name of consultant organization], we had a lot of different change guides for us -- how do you manage change, and how do you support the concept of making these changes? We started using them more when we our created our DEI committee in-house. We created this committee. You really needed this leadership to occur so that you could get people on board…These frameworks that we used, these different guides that we got from the university, we tried to make sense of them for us and integrate them into what we're doing. We used a couple of different ones."

Table 11. RC Directors' responses to whether or not a logic model was used to demonstrate the correlation between advancing equity and disparities reduction within their grant project

Coding Structure	Frequency	Illustrative Quotes
No	7	"Nope. I don't think we did that either. It would have been too difficult for us to train staff on that, and be able to do that effectively. I would say no, we did not."
Don't know	6	"I don't know how those were developed. I saw the outcomes, but…I can tell the time, but I don't know how the clock was made at this point."
Not formally	2	"We did. If we didn't, it's still there because of the inputs, lots on the inputs and things like that. Again, anytime we have a screening, reaching out in that area, from the parks and recs to newspaper to flyers, all of that, it's definitely incorporated. I'm not positive if we formally put it into the grant or not."
Yes	2	"Yes, we did. The navigation program, we knew it was going to be evaluated. We obviously put some measures in place that we felt were reasonable. We have exceeded all the goals." "In the person-centered thinking, there's different things that you can use for your group. We tried to use them in our change model. Most of it was around the DEI efforts that we were involved with, in trying to get people onboard and understanding why would it be important, explaining it."

Table 12. RC Directors' responses to whether or not they engaged persons with IDD and their families to evaluate supports and services provided by their SAE grant project

Coding Structure	Frequency	Illustrative Quotes
Yes	11	"We've also had events where we got testimonials from families in terms of how the program went. Any feedback and how it went." "Small group meetings, outreach, a little bit more difficult in 19-20, or especially towards the end of 20 because of COVID. But again, more community outreach, a lot of staff activities, board engagement, vendor advisory, other parent groups. Yes." "We have a small group. Well, all of them are invited and they don't all have a hundred percent participation or attendance at every meeting. We have quarterly meetings now where we still invite all of these groups and ask them to come. They give us input there. Then when we go to their community, their regular meetings, we get invited. If we get invited, we go. We solicit support and information then. Then we have public hearings as well, and we invite folks to communicate at that level. Then we have board members as well on our board who are from the parent groups or who know folks in the parent groups, or who are speaking from a parent perspective or from a community perspective in terms of what's going on."
No	4	"We did not. The biggest reason why that didn't occur was due to the COVID disruptions. We were not able to do the follow-up necessary to evaluate the impact of the grant project. The regional center, we worked remotely for over a year. The disruptions made it too difficult."

Table 13. RC Directors' responses to the most significant challenges in implementing their SAE grant project

Coding Structure	Frequency	Illustrative Quotes
Cultural and linguistic barriers often leading to a lack of trust in certain communities	7	"Getting that population to open up to us, to engage with us. Even with having a member of their own tribe working with us and reaching out to them, it was still and continues to this day still to be very challenging." "Part of it is cultural. Whether or not a culture feels more like, 'This is my family. I'll take care of it,' as opposed to reaching out to others, or trusting other entities, organizations, specialists to assist. Those were some of the things. Then, not trusting, not wanting to trust outsiders."
Lack of adequate resources (mainly lack of staff and funding)	7	"Then just being a huge area that we cover. I think from tip to tip, it's well over 200 miles from the top of my county to the bottom, even more than 200 miles, and then everything in between. How does one Regional Center cover all these people that are all very different?" "In these years, the most difficult challenge was getting staff. We just simply without the money didn't have enough bodies to do it. Then this year when we asked for an extension of funds trying to hire someone, we couldn't find people to hire." "My team are ready, they're passionate, but workload impact. How do I get people to not burn out while we're trying to do this amazing work that we're trying to do?"
COVID-related challenges	5	"Over the past few years, we can't minimize the impact the pandemic has had. I say it in a way that I can speak firmly that I know that it has highlighted and exacerbated disparities. The pandemic didn't cause disparities. It exacerbated and highlighted them and put more light, rightly so."

Table 13 (continued). RC Directors' responses to the most significant challenges in implementing their SAE grant project

Coding Structure	Frequency	Illustrative Quotes
Unrealistic implementation timeline	3	"The other impediments, I would say, would be the timeline for how the grant monies are supposed to be expended. It leaves the regional centers about a three-month period to finalize how the monies are going to be spent and contracted once the grant is awarded. That doesn't give us a lot of time to effectively work with the community to identify where the monies can be spent most effectively."
Underestimating families' needs and support related to technology	3	"We had worked in some staff support in the homes, but that got to be a larger need than we had suspect that they needed to learn everything about the technology where we were assuming it was mostly learning how to get onto Zoom and that kind of thing. Those were some of the greatest challenges. The lack of technology, understanding, and our underestimating how much support people would need even to start the iPads up and get ready to move around them."
Lack of guidance regarding deliverables, expectations, and partnerships	3	"Lack of clarity from the department. In the beginning, even the department didn't know what they wanted. Even the department wasn't sure what to target. I think that we were going blindly here. There was framework, but there was no well-defined, in my opinion. That was a little challenging for us, because we wouldn't get communication from the department. Then, we would get follow-up communication that didn't necessarily correspond with the previous communication."

Table 14. RC Directors' responses to whether or not their SAE project worked directly with persons with IDD and their family members from racially, ethnically, culturally and linguistically diverse backgrounds
i. If yes, what barriers were encountered in these efforts?

Coding Structure	Frequency	Illustrative Quotes
Yes	8	
Barriers encountered		
Lack of attendance from families due to time restrictions	3	"In many cases, the flexibility of regional center schedules. The service coordinators, the system itself is kind of this Monday through Friday, as I said business and families are in need and in crisis, and twenty-four hours a day, seven days a week. So, we have an on-call number, if you will. But that's just a phone number, it really isn't that...doing service coordination."
Varying interests and needs to proposed programs	2	"The model in that grant project was to develop a certain residential-type service, the family home agency. We had two different groups who were working on that, with the Deaf community with IDD, and then the Cantonese and Vietnamese population. We found that the Deaf community was engaged in terms of people being interested in residential models. We found that when we looked at the Vietnamese and Cantonese families, they didn't like that model after we introduced it. They felt like it was too much like staying in their own home. There were some different interests in what it would be. A lot of families felt like the model of a family home agency wasn't exactly what they wanted."
Lack of trust from families due to legal status	2	"I think that fear of the regional center reporting them if they have any kind of immigration issues. Obviously, we don't do that. We make a point of it to let the community know that we're not involved in that. There's always this fear within the Hispanic community -- certain individuals or families have immigration issues -- that we're somehow going to report them. That's huge. It's probably bigger than we even realize."

Table 15. RC Directors' responses to the most significant outcome from their SAE project in terms of disparity reductions

Coding Structure	Frequency	Illustrative Quotes
Increased family and community engagement, partnership, and trust	8	"Building trusting relationships with the community, and doing whatever bridge-building we can do to support the individuals. To help them feel more comfortable in working with us and reaching out to us, and allowing us to provide services to them." "I think that we've established some good relationships with some community partners that if there are issues, they will tell us more. We've got so many things in place now to talk to people that we didn't in the past."
Increased populations served and POS expenditure	4	"Disparity reductions, one would be I've seen situations where people did not have services where they start getting services, so we start seeing increases in expenditures. I think that's what it's about, is getting people connected to the services." "In some ways we set ourselves up for more disparities because we almost doubled our Latino population. That's a pretty significant positive outcome, is that we're serving more people. Disparity reduction, my Latino population right now, today, has the smallest disparity."
Resource and capacity development	3	"The most significant has been the continued use of our booklet. We've modified it along the way, but it continues to be used for a lot of trainings. It's being used by our community partners. As we've modified it along the way, they've been integral in helping us get the word out. That has been a real positive and lasting effect of the SAE grant."
Increased families' knowledge of RC services	3	"Families and individuals had a much greater understanding of what they could ask for from the regional center. There were sessions on supported employment and employment in general. There were sessions on conservatorship."

Table 16. RC Directors' responses to the types of data collected to document disparities reductions

Coding Structure	Frequency	Illustrative Quotes
Evaluation surveys and questionnaires	8	"Then the team also did some surveys, I believe as well, and was asking about satisfaction and feedback about what's going, and then there's the anecdotal. There's a lot of good work that happens that can't be measured completely." "We did a survey specific to our Spanish-speaking population, and then we did a more general survey about individual and family satisfaction. We can look at those response rates or response scores, but other than surveying people, I don't have a lot of good data about whether people are satisfied on an ongoing basis, or whether they're experiencing barriers on an ongoing basis."
POS and aggregate expenditure reports	7	"For disparity reduction, we would use our expenditure reports, so specifically looking at individuals who were connected to the grant or connected to the project with their services, did they have any services in place? Were there issues? Challenges? You can see data point that way" "I don't know if we track by individual, by folks that came in, my guess is that we have not. It's just that aggregate data in terms of this is how much money we spent on children birth to 3 that are white, African American, Hispanic, and they're really just big numbers."
Anecdotal	2	"I wish I could tell you that I track family A, D, and C, here was their pre-data, here was their post-data. I would need an entire new statistician position to crunch numbers for us, and we can't support that kind of position. The data we have is more anecdotal."

Table 17. RC Directors' responses to data collection and analysis efforts on SAE project findings in the following categories

Coding Structure	Frequency	Illustrative Quotes
Race		
Yes	12	"All of the data in the regional center, every single thing can be queried with relationship to race, language, or ethnicity."
No	1	
Not sure	1	
Ethnicity		
Yes	12	"Yes, we are now calibrated to review all of our data by ethnicity and race."
No	1	"I'll be honest, we usually look at race and ethnicity as one."
Not sure	1	
Languages Spoken		
Yes	11	
No	2	"The reason I say that [no] is we collect data on the ethnicity and language preference of individuals that are directly served by the regional center, but we don't collect information about what language is spoken by the families."
Not sure	1	
Geographic Locale		
Yes	10	"Yes, we do. We do look at that to see what those differences are. Typically, we know where the high Hispanic area is. We do combine all of those zip codes to see, is there a greater discrepancy between [these areas], some of those. We look at it from those three vantage points."
No	3	
Not sure	1	
Socioeconomic Status		
Yes	2	
No	11	"It doesn't come into play because we are just here to meet the needs of the individual with a disability."
Not sure	2	"Socio-economic, I would doubt, I'm not sure, that's just entry contact data, not ongoing data."
Other Factors		
Age	5	
Disability/diagnosis	3	
Expenditures	2	"We looked at expenditures, of course, what was being utilized. If there were increases, hopefully not decreases, it get connected to us, but usually the opposite around getting increases there."
Referrals	1	"Now we're looking at referral source. And those things, and then trying to do more in terms of follow through, not just a screening, if you will, for young kids. But what was the outcome of that? What was the assessment?"

Figure 2. RC Directors' responses to data collection and analyses efforts in the abovementioned categories
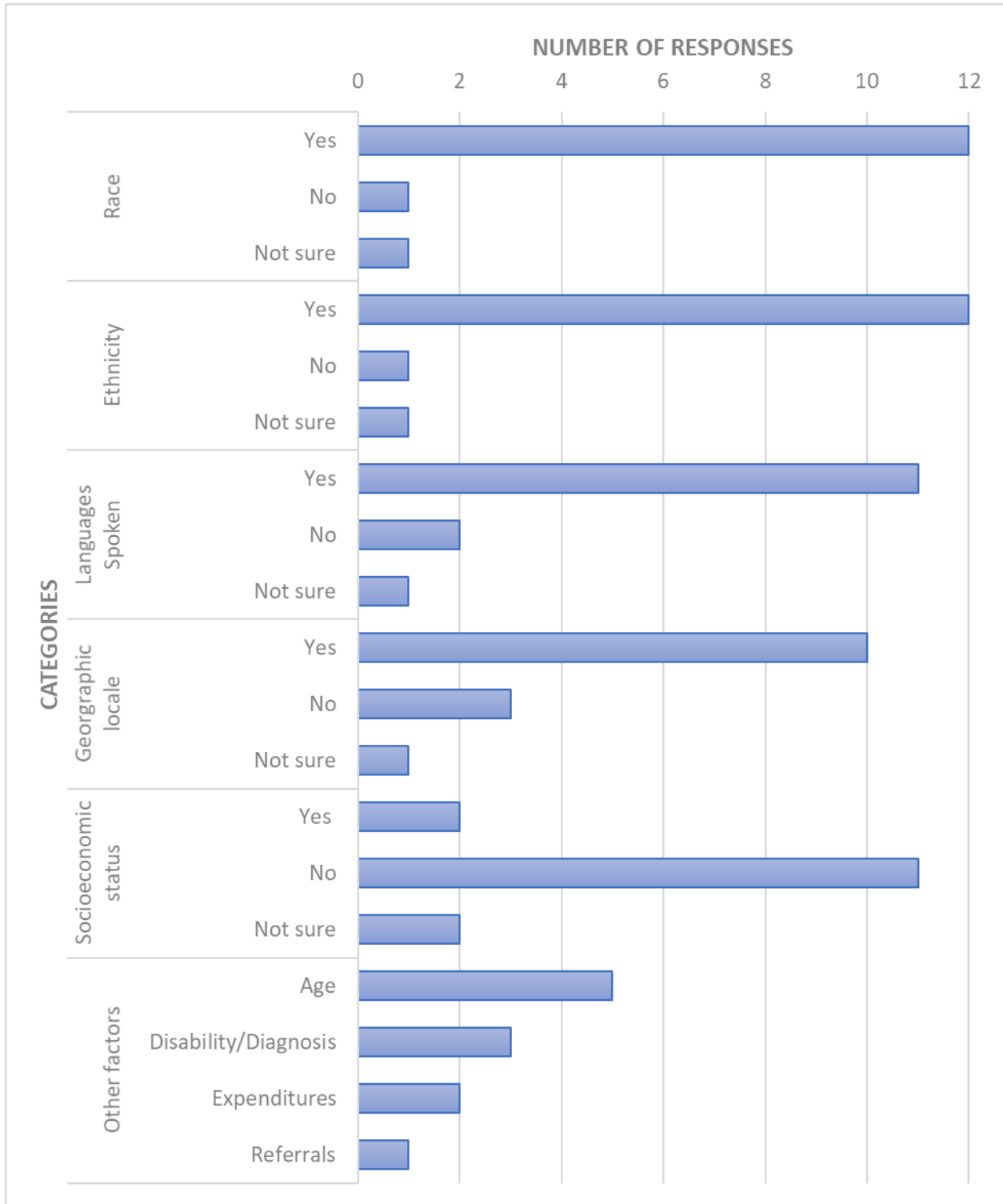
Table 18. RC Directors' responses to their current capacity for collecting, analyzing and reporting on disparities data for the SAE program

Coding Structure	Frequency	Illustrative Quotes
Low	8	"I would say it's probably low capacity, to be very honest about it. We've got only a team of two people who pull the data. We've got one person…that leads the efforts of analyzing the data." "I'm going to say we have no capacity…We don't recruit employees with that skill set, because it's not core to the work that we do. Then that means you need to find a good consultant that you can utilize." "I would say low capacity and only relying on our SANDIS system."
Moderate	5	"I'll say moderate, maybe. We're just manually doing it, we don't have a mechanism. I would say, you're right in the website. We're trying to use survey monkey stuff like that to collect, to kind of tap into folks and see what works for them." "I would say moderate. We've had to build a Power BI to be able to look at data. The state system that we have, SanDisk, is so archaic. You probably hear this from everyone you interview. It does not tell us. It does not let us break down information."
High	2	"I'd say it's high. We're actually, in some ways, probably in better shape than the other regional centers because our population is so small."

Table 19. RC Directors' responses to whether or not their SAE project led to an increase in the following areas

Coding Structure	Frequency	Illustrative Quotes
Availability of supports and services		
Yes	10	"Yes. 100 percent…Getting connected, I get examples and I see individuals that were not connected, that did not have a good experience, that did not trust, that did not have the information they needed, that now has information, that's now connected. That invites other people from an experience to come talk to us."
No	1	
Not sure	1	"Without seeing the data. I really should not answer. I would say, don't know would be my best guess here."
Accessibility of supports and services		
Yes	10	"I think that answer is also yes, because we set it up designed for people who speak Spanish."
Not sure	2	"I'm not sure we have data in terms of the kind of the accessibility supports and services."
Acceptability of supports and services		
Yes	9	"I would say yes…We've been having a lot more of these conversations about why you would use them [services and supports] or how they could be used differently. That has made a difference for people."
Not sure	2	"I don't know. I hope that by having better information -- and, at least, in Spanish -- that maybe that area was positively impacted, but I don't know for sure."
Quality of supports and services		
Yes	7	"So, looking at that supports and services, the quality component for some families, I'm sure we've done a great job on a lot of that."
No	2	
Not sure	2	"That wasn't the focus of the grant, so I don't know"
Utilization of supports and services		
Yes	8	"Great numbers. Good numbers. It's definitely all the avenues that we get the word out and all those things are still very effective because we have easily up to a hundred or more sometimes at a developmental screening for a day."
No	3	"Utilization plummeted. COVID dropped everything right through the floor."
Not sure	1	"Again, my hope is that that was positively impacted, but I don't know. Again, because of all the disruptions that were caused by COVID at that time, we're not able to do the follow-up."

Figure 3. RC Directors' responses to their SAE projects' impact/increase in the supports and services of the abovementioned areas
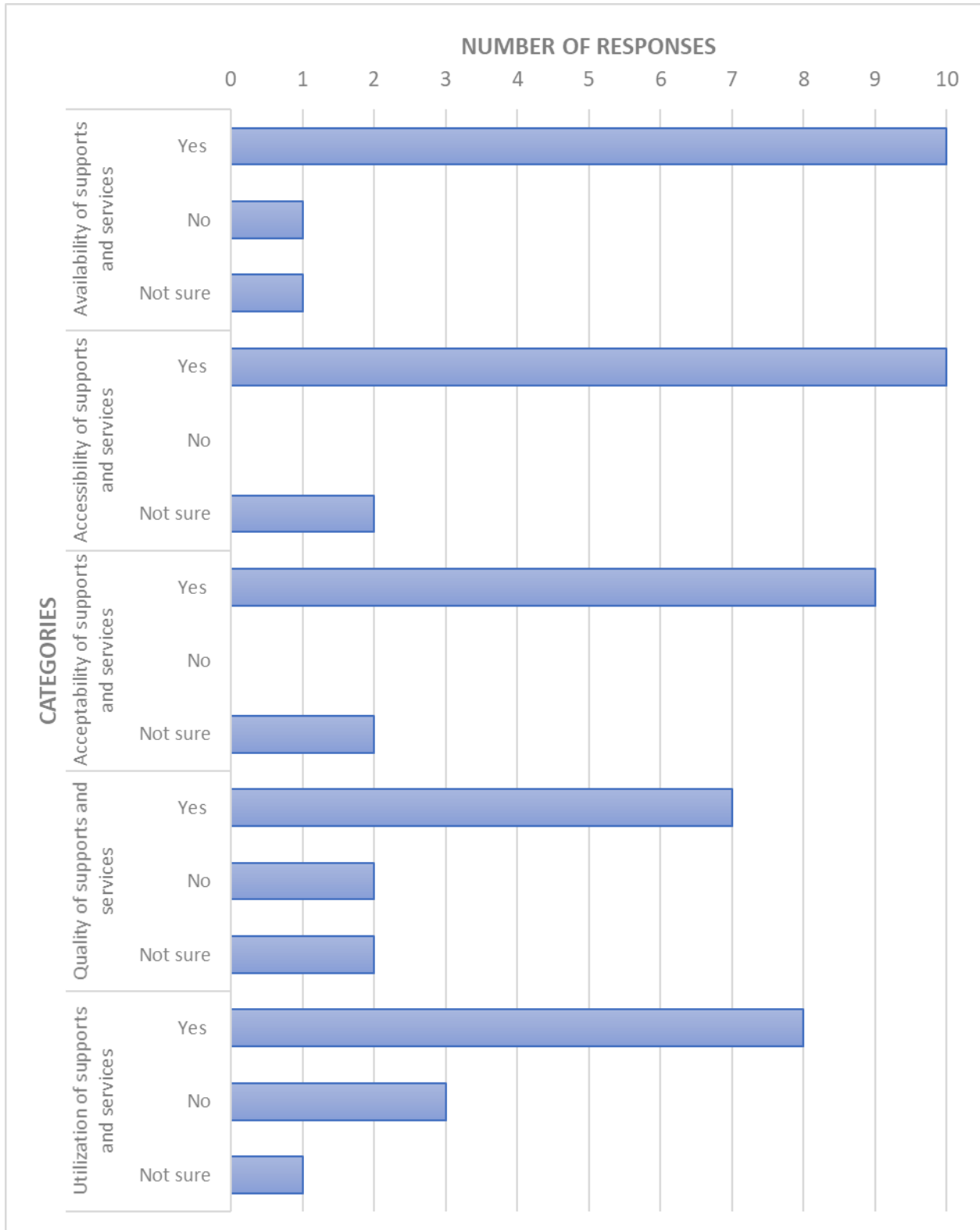
Table 20. RC Directors' responses to the strategies used with their SAE grant activities to reach potential individuals with IDD and their families that are unknown or not receiving services through the Regional Center

Coding Structure	Frequency	Illustrative Quotes
Focused outreach and partnership	8	"We targeted them. We had targeted mailings that went out to families, and we also used our community partners to help us reach these families. At the beginning, we use three or four community partners for the regions that helped us in reaching these families and offering more intense support." "The strategy was to try to increase that outreach, provide training. Give them information about our services. Give them information and workshops, things like that, to try to get them more engaged, to get them to engage with us."
Advertising through media and print	4	"We do a lot through technology, social media, website, we have a Facebook page in English and Spanish, we have an Instagram page, English and Spanish. We now just purchased a professional TikTok account, never would have thought that that was a thing, but apparently, that's what professionals do. We're now on TikTok, or we're going on TikTok as a platform."
Partnership and collaboration with local government and community organizations	2	"For me it's always been working with our county, our city staff as well so we're not duplicating efforts, something that we should definitely do more of and do a better job of working with our legislators in terms of their outreach efforts, I think it's been successful. We're working, I think, very closely."

Table 21. RC Directors' responses to the importance of the grant program to their Regional Center's efforts to decrease disparities among persons with IDD across racial, ethnic and linguistic groups

Coding Structure	Frequency	Illustrative Quotes
Very important	12	"I would say it's extremely important. We could, we have tried before without the grant, but when you don't have dedicated funding, dedicated folks doing certain things, it's going to be set on the side." "Well, I'd say it's very important for the continued effort. We lost momentum when COVID hit. We want to continue with the momentum. We want to continue to be able to reach those populations so that those services can be provided. It will take time and unfortunately, like I said earlier, we lost time. We lost our progress. We slid back. We're going to move forward." "I think I've said it already, frankly. Without that money, without the resources that we did receive, and that we are receiving from the grant, I don't think we'd be close to where we are right now. It was the boost we needed and it's the support we needed to do that. It was significant. It had a significant impact."
Important	3	"It's important in the sense that it has allowed us to...It has provided funds for us to hire specialized staff to create materials that we think will provide more information, and create greater access and understanding of services. In those senses, it's important, in the sense that it has the power to solve the issues. It's such a big issue."
Not too important	2	"There are actually not that important among our efforts. I'll say that because the grants, they're one-time kinds of grants. For us to develop services that people want in our region, to develop a home, we need $750,000 at least. These grants don't have that opportunity."

Appendix B

Qualitative Coding Tables: Service Access and Equity Project Manager Interviews

Qualitative Coding Tables: Service Access and Equity Project Managers Interviews

Listed below are the coding structure and illustrative comments that emerged across all thestructured interviews convened with the SAE Project Managers (n=16). Table 1 and Figure 1provide the number of years participants served as an SAE Project Manager. Tables 2-21 present the coding structure with frequencies and selected delineative quotes.

Table 1. Years in role/current position

Years as an SAE Project Manager	Frequency
1-2 years	5
3-4 years	2
5-7 years	7
8-10 years	2

Figure 1. Self-reported number of years served as an SAE project manager

Table 2. SAE Project Managers' responses to the racial, ethnic, and linguistic disparities among people with intellectual and developmental disabilities (IDD) in their region

Coding Structure	Frequency	Illustrative Quotes
Disparities in underrepresented and underserved communities	7	"Based on the data that we have, we have clear disparities for underserved communities. The communities that have the most representation are Hispanic, Latinx. Then we have African American, multicultural, Tagalog-speaking families. Those are the top groups." "Disparities, when it comes to minority groups, it's not just Hispanics. We have a discrepancy when it comes to African Americans, Native Indians, Native American Indians, Hispanics, ASL. There is disparity on the minority groups. I've been working closely for years to look at the reason why the discrepancies are happening." "The disparities, language barriers, cultural barriers especially for the agricultural workers that were largely Latinos and Hmong or Mien. That would be both linguistic and/or cultural."
Disparities in POS and funding	4	"Where we see the largest disparity and looking at the largest numbers presented in different ethnic groups would be our white Caucasian communities and black African American receive higher funding, more amounts of funding in comparison to our Hispanic or LatinX communities, as well as our Chinese communities. We also see that same disparity within our Filipino communities, Vietnamese, Korean, Russian, Native American." "What I have observed is that if a consumer is white and the consumer's primary language is English, the Regional Center of the East Bay spends more money on those individuals than on individuals who identify with other ethnicities or races, as well as identify as speaking other languages different from English as their primary language. That, for me, it never makes sense."

Table 2 (continued). SAE Project Managers' responses to the racial, ethnic, and linguistic disparities among people with intellectual and developmental disabilities (IDD) in their region

Coding Structure	Frequency	Illustrative Quotes
Disparities in diagnosis	3	"Though, there's a disparity in diagnoses and how you're interpreting behaviors. With people of color, sometimes there's a proclivity with some psychologists to see that their behaviors are a manifestation of some sort of mental health [issue], whereas with Caucasians, more of a prevalence, a manifestation of Autism Spectrum Disorder."
Racial disparities in type of services provided	3	"Clients who choose to transition to live independently or live in a care home setting, those individuals tend to use more regional center services, and those individuals tend to be disproportionately among the White and Caucasian populations."
Disparities due to age	2	"Most of our disparity statistics that we've gone through every year, we see that the largest disparity is in adults 21 and older, between per capita spending for each individual"
Disparities due to privileges	2	"Those in the higher income obviously, they can be more likely to be litigious, more likely to have legal representation. When there are appeals or appeal hearings, there is a feeling that they will regularly appeal and get what they want as far as service distribution."

Table 3. SAE Project Managers' responses to the root causes or factors that contribute to disparities in California's system for persons with intellectual and developmental disabilities (IDD) and their family members from racially, ethnically, cultur ally and linguistically diverse groups

Coding Structure	Frequency	Illustrative Quotes
Lack of trust in authority and government	10	"There's a lot of people that are grateful to get what they get. A lot of Hispanic families that don't want to rock the boat, especially if there's pending immigration issues. They don't want to be identified. They see it that they're going to have a black flag against them if they're impending on the system. It's not true. There's very limited understanding of how to navigate our system, and how you can request things, how you can appeal them, how to navigate an appeal successfully." "Another factor I would think is the mistrust of the authority and the government agency. They see the Regional Center as the authority. Therefore, there is always the barrier of the law between Regional Center and the families or the persons served by us."
Lack of cultural and linguistic considerations	10	"Language accessibility is definitely another problem. With the first rounds of grants, we tried to address that by establishing and funding startup programs geared specifically to some populations in their language and culture. That is the only year when I saw the needle moving in the right direction." "Additionally, we have a lot to learn about how different ethnic groups or cultural approaches to one disability, what that means in their family. Then what it means as far as being in a position to ask for assistance. I think that we as a system don't embrace enough that, when we have families that maybe immigrated into our communities, one access in their communities may be very different than access here. Access from one state to the next is very different, right? Then you add a different country. Also, what it means to, from a cultural perspective, do something that is looked at as taking assistance. That has very different values across the board. Services that involve having people come into the home. That's going to be a factor. That's not something that everybody is comfortable with."

Table 3 (continued). SAE Project Managers' responses to the root causes or factors that contribute to disparities in California's system for persons with intellectual and developmental disabilities (IDD) and their family members from racially, ethnically, culturally and linguistically diverse groups

Coding Structure	Frequency	Illustrative Quotes
Irrelevance of the Lanterman Act supports and services to community needs	8	"As a system, we build it on independence and what that looks like from an American belief. A lot of times, those were very much aligned with White/Caucasian values." "These are systems that weren't built with people of color in mind, minorities, people who don't have access to education or wealth. These systems have been built by people who had certain privileges and created for those with those certain privileges." The law -- a beautiful law, the Lanterman Law, a beautiful system -- is very inadequate culturally speaking, and that costs a lot of money."
Illiteracy and technological barriers	7	"I've seen technological issues with some communities depending on their race and ethnicity. Definitely came out during COVID, when we moved to alternative services." "Something else that I saw with older immigrant populations was illiteracy. Again, more on that, I have more experience with the Latinx population up there because I am Latina and Hispanic myself. I remember I had a couple of parents that wanted me to write some things down for them, because they could not write. They could barely read." "A lot of the services have shifted into being online. For example, respite. If you want to submit your timesheet for respite, you have to do it online. That's a problem. What do those families do that don't have access to Internet or have low literacy when it comes to navigating the Internet?"

Table 3 (continued). SAE Project Managers' responses to the root causes or factors that contribute to disparities in California's system for persons with intellectual and developmental disabilities (IDD) and their family members from racially, ethnically, culturally and linguistically diverse groups

Coding Structure	Frequency	Illustrative Quotes
Personal circumstances	5	"Without getting food or rent in the first place, it's hard to then think about your kids' physical therapy, speech therapy, or whatever else it is that they will need for their disability if they can barely put food on the table." Well, I think also it's a lack of time for a lot of parents, because they are working minimum wage jobs, they're out in the field for up to 12 hours a day. There really isn't a lot of flexibility like, for example, you and I to hop in a Zoom meeting. Some of the places that I will go out there, they would have no cellular signal, let alone WiFi."
Complex systems of supports and services which are difficult to navigate and understand	5	"I think that definitely the complexity of our system is a problem" "I would say the special education system is definitely lacking. I think they're very behind. I hear a lot of negative things when it comes to working with school districts, accommodations for people's children, not understanding the IEP process and kind of just going along with it. Interpretation…signing documents they don't understand. So, I think all those things impact the transition and access to resources and services." "They are [families] having difficulty accessing those services, so a lot of, I would say, handholding or walking people through the steps, because there's no education about…how do you access these services, what services are available, the distinction between where do regional centers start funding versus the school district. You know, so many different aspects.
Lack of knowledge about services and service navigation	3	"There are some perceptual distortions too with some of our families, where there are a lot of perceptions of different barriers that are not always realistic. For example, when considering residential options, there's an understanding. I've had a family tell me, for example, 'Well, if I use the residential option, I'd never be able to visit him again.' I'm like, 'What the...that's not true. You can visit him and he can come home.'"

Table 3 (continued). SAE Project Managers' responses to the root causes or factors that contribute to disparities in California's system for persons with intellectual and developmental disabilities (IDD) and their family members from racially, ethnically, culturally and linguistically diverse groups

Coding Structure	Frequency	Illustrative Quotes
Large case loads	4	"High caseloads at this point are huge factors, and lower caseloads, we would be really able to mitigate those barriers, I think, with lower caseloads." "I think time. The time that service coordinators do not have, again, to spend with families"
Stigma associated with needing care	3	"First and foremost, the initial barrier is overcoming stigma associated with conditions that would qualify for eligibility diagnoses, seeking diagnoses that would allow someone access to the regional center service. Once eligible services are being based on need, stigma associated with presenting oneself as having needs.
Lack of resources and staff	3	"And the biggest issues there are the lack of resources, and organizations that provide services for people who have DD [developmental disabilities] and IDD [intellectual developmental disabilities]. "The other thing is that, because the rates are so low, our programs are not competitive. People are not encouraged to establish this kind of business because it's not profitable. It has to be profitable for someone who wants to enter this field and serve our population."

Table 4. SAE Project Managers' responses to the current status of disparities in Purchase of Services among the racial, ethnic, and linguistically diverse populations supported by their Regional Center

Coding Structure	Frequency	Illustrative Quotes
Racial disparities in types of services offered	5	"When we compare people living at home versus people living out of home, we see a higher disparity between what is spent and authorized for individuals in the white Caucasian community versus other ethnicities. We also see, as far as accessing or residential placement choice, a larger number of individuals who are white or Caucasian living in out-of-family home environments than our other ethnicities. I would say it's our white and Caucasian and black African American. In comparison to our numbers with our Hispanic, Chinese, and other non-whites -- groups of color -- we see a higher rate of individuals living at home"
Moderate improvement and progress in addressing disparities	4	"We are slowly improving. This position got created in March this year. I would like to see more. I would like to see more change at a faster pace. Again, change is slow when it comes to historical racism."
Disparities in adult and transition services	2	"When we've looked at early start data, we didn't really notice any disparities or differences in our purchase of spending. Moving over to children, again, not as much, because for the most part they're getting services from the school district. So, there's very special cases in which children would access services from us. For the most part it's going to be like daycare and respite. And then once we move to transition age use, that's where we start seeing the differences in spending…for probably different reasons. But the disparity shows up in transition and then in adults. A big reason being residential services are our most expensive service, and not everyone is comfortable with accessing that service."
Lack of progress in addressing disparities	2	"Yeah, pretty much I have stated that I have not seen much difference between six years ago, when the program started, and today, when more programs are being funded to address these issues. Instead, what I have seen is more a change in the narrative."

Table 5. SAE Project Managers' responses to why their Regional Center decided to submit a proposal to DDS for its Service Access and Equity program

Coding Structure	Frequency	Illustrative Quotes
Parent education and training to improve service navigation knowledge	5	"We focused a lot on trainings with the individuals that we support. We focused the trainings around transition points. For example, individuals transitioning from early start into children's units over three. Then, children transitioning from high school into adult, and provided a lot of...We had seminars and trainings for families to educate them about changes and service options. I was the one that suggested that we do the peer mentor cafes. It was because I had seen a similar model through another agency with parent cafes…I felt that it was a similar model that we could adopt and have a moment with our parents and our clients to sit down and talk and see if maybe, through conversations, we could get at some of the other root causes of why they're not using their services, why do they not trust their service coordinator, or anything else that could come up."
To address family needs in terms of transportation access	3	"The first one was a transportation grant, and that was to eliminate, or at least reduce transportation barriers for families that were facing financial struggles or not having a vehicle, not owning one, to be able to attend trainings and conferences."
To improve caseload management	3	"When we were looking at applying for the grant initially, it was with this idea in mind that perhaps by having a reduced caseload, service coordinators would be able to make a bigger difference in regards to assisting families with accessing needed services, specifically in the court supports as well. That was, I think, the original idea of our project."
For increased funding and resources to address disparities	3	"I think it was just a natural feeling that if there is money available to address inequities. At the beginning, we thought that that was the answer."

Table 5 (continued). SAE Project Managers' responses to why their Regional Center decided to submit a proposal to DDS for its Service Access and Equity program

Coding Structure	Frequency	Illustrative Quotes
One on one support services for monolingual families	2	"We also wanted to provide support, one on one support to these families, since you know, through the service coordinators, there's a lot for them going on, so I think, having this one on one support with the parent, it was very beneficial…and needed at the time."
To maintain services provided to families	2	"One of the reasons that the Regional Center decided to submit the proposal to DDS is we want to host the developmental screening. Our subcontractor, they have been doing developmental screening in [this County] for many, many years. Before Regional Center came in, they had a different funding to host the screening, in-person screening, with licensed therapists. It costs money. They used to have the funding, but the funding got cut several years ago. We wanted to continue doing it, and that's why we decide to submit the grant to DDS."
Sub question: <u>Is this project expanding capacity or is it new work?</u>		
Expanding capacity	4	"I will say that is expanding in the capacity of what will be service coordination"
Creating new work	5	"I would say it was new, based on the community navigator model. It wasn't something that is commonplace right now, with the regional center."

Table 6. SAE Project Managers' responses to their Regional Center's definition of equity for persons with IDD and their families

Coding Structure	Frequency	Illustrative Quotes
Equal access to information and opportunities	7	"In our conversations, in our language, in our jargon, what we understand for equity is equal opportunities for everyone to access services, and also the elimination of barriers that prevent people from having full access to the services." "I say in a lot of things that I talk about, is the information equitable to everybody we serve?" "[Our regional center] strived to give equal opportunity, to give resources, and give them the opportunity to choose whether they wanted services or not."
Focuses on a culturally and linguistically tailored approach for individuals, families, and communities	5	"We see equity as meeting the family where they're at, taking their cultural considerations into account and then guiding them to a place where they're getting the things that they want and need, because they're going to be different from someone else's."
No explicit definition	3	"It just depends who you ask…there's various issues that are kind of like a domino effect. So, I think, as an agency, we're very aware that those are the issues. But how we define equity varies at [this regional center]. That's why we're not, maybe fixing some of those things."

Table 7. SAE Project Managers' responses to the levels their project was designed to mitigate disparities

Coding Structure	Frequency	Illustrative Quotes
Family	15	"An in-depth, online training platform for families, to give them all the knowledge of all the service options and how to navigate them. We would give them to families when they are transitioning, for example, into our Children's Services, when they are transitioning into Adult Services."
Individual	14	"For sure, it's individual level because we screen the kid, we give them the services that they need."
Community	12	"Community, yes, because we actually try to reach to the community. We try to serve the community, especially the underserved population." "We do make connections for the organizations in the community, not only write to address issues with equity, and provide information is what we do but also to work together."
Organizational	8	"It definitely has had an impact in that. We've been in the last five years…everybody knows about the reduced caseload project. Obviously, we're working with individuals throughout case management, and so service coordinators are familiar with the work that's happening in the enhanced caseload. When we've been deliberate about putting processes in place to share the lessons that we're learning, to inform them about the barriers that we're seeing, so then they could bring that back to their individual meetings and hopefully be able to mitigate some of those barriers as they come up in their own caseloads."
Systems	4	"Since we were the first ones to implement this model…Since then DDS has been looking at implementing this at all regional centers and working on the POS [name of model]. I think our data and our project and the results have, you know, pushed DDS to continue to fund for this specific kind of program."

Table 8. SAE Project Managers' responses to culturally competent approaches used to implement the grant, specifically in supports, services, and project activities

Coding Structure	Frequency	Illustrative Quotes
Culturally representative staff	4	"Seeking out and specifically hiring individuals of those language, linguistic, and cultural backgrounds to serve as the liaison for connecting clients with regional center, regional center services, and generic resources."
Seeking partnerships and consultants for outreach to underserved communities	4	"We partnered with two local CBOs that were close with the Latinx and the Mien and Hmong communities. With that, in order to help promote more of the program, they both held different cultural programs. One of them was a fiesta. The other one, I think it was a New Year's celebration."
Culturally focused resources	3	"Also, incorporating different metaphors that would be culturally relevant for African American and Hispanic families. We thought about the symbols and the metaphors that we were utilizing, that would also resonate with different populations. Also, in the materials that we were creating, the visuals that we were creating is having visual representation of Hispanic, Asian, African American, and white families. The visual depictions and the symbols would be more broadband."
Listening to and responding to families' needs	3	"We also looked at whether or not they had Internet access so we'd know if we needed to provide that access as well. If they needed support in learning how to use a device, things like that. That was done all in Spanish. We provided information on how to set up for Zoom, how to set up a tablet -- all of that in Spanish. We coordinated drop off of devices with each family."

Table 9. SAE Project Managers' responses to linguistically competent approaches used to implement the grant, specifically in supports, services, and project activities

Coding Structure	Frequency	Illustrative Quotes
Improving language access in resource development	5	"Yes, absolutely. All of the fliers that we produced are done in multiple languages, depending on where the screening is going to be held. It's really [name of partner organization]. I applaud them for making the effort to find the professionals who fit with where the screening is being held as much as possible. Sometimes, we can't." "We made sure that we were presenting all the information in the manner in which every person, every participant was able to understand and grasp. I think that we, again, were very sensitive to language needs."
Having staff who speak the languages of the families/ communities of focus	5	"The promotoras had to be bilingual in the languages that we were targeting. They had to be Spanish-speaking for the Latinx community. We had a couple that were Hmong speaking, and one that was Mien-speaking. We wanted to make sure that they were able to speak the language and know the culture of the folks that they were trying to serve." "Yes. As I mentioned above, we will have staff that speak their native language be there at the site to assist them in communicating."

Table 10. SAE Project Managers' responses to whether or not a theory of change framework was used for their grant project

Coding Structure	Frequency	Illustrative Quotes
Yes	5	"We kind of use our own framework that kind of took from both of those theories…so, we they developed our own framework to determine what kind of interventions would be needed, based on the individual level, supports, and then systemic needs."
No	5	"I don't think we did specifically, no."
Not formally	4	"We did not necessarily use theory-of-change specific language. In fact, I worked that definition that you had just in the questions. To the extent the questions allowed for us to do that, that was a focus as far as what we were proposing to do, what we anticipated as change, why it would be important to do that. In this case we were able to draw a correlation between previous [project] that we had done and the feedback that we had heard."
Don't know	2	"I'm going to say I don't know, because I love this term theory of change framework, and I'd love to do some more studies in it, so I can't speak to it because I don't understand the concept as well."

Table 11. SAE Project Managers' responses to whether or not a logic model was used to demonstrate the correlation between advancing equity and disparities reduction within their grant project

Coding Structure	Frequency	Illustrative Quotes
No	6	"No. That's where I would point to some of the feedback about how the [grant] questions were formatted. I don't think historically the questions have been formatted well to draw some of those correlations."
Yes	3	"Yeah. I would say over the years that we've been doing this"
Not formally	3	"There were not a lot of illustrations of it, but there certainly were descriptions of proposed outcomes in terms of how many families would have a Promotora and would use their Promotora and if that would lead to a higher POS ratio so to speak."
Don't know	3	"I would say that's another thing that I would definitely say I'm not sure, but I do feel that was it. I would say it looks that way, but I don't know if that's how initially they decided to use it."

Table 12. SAE Project Managers' responses to whether or not they engaged persons with IDD and their families to evaluate supports and services provided by their SAE grant project

Coding Structure	Frequency	Illustrative Quotes
Yes	12	"Yes! Every family that goes through the program at the beginning, there's a baseline assessment that goes through their knowledge about their developmental disability, stress and depression, services that they're aware of. Those kinds of assessments are done at the end of every session, there's a fidelity done. And then at the end, they have their end of service assessment, which again has a lot of the same questions that we asked at the beginning…And so we've got an input through there. We've also had events where we got testimonials from families in terms of how the program went. Any feedback and how it went." "The whole thing, it was involving the individual and their family from the beginning to the end. We developed ways to measure out, that was really something that I wanted to do. We felt that it was important, so we developed ways to measure all of our outcomes. Again, I think that that's one of the reasons why our data continues to be easy to understand and shows the progress that we've made. That was engaging families from the beginning, as soon as the enhanced service coordinated. The first concept that they had was to do a pre-survey with the family to understand their level of knowledge regarding the regional center system. It was a very clean meeting. That was the main purpose of that meeting. Subsequent meetings involved getting to know the family and conduction an in-depth assessment of their needs, which led to our questionnaire. We had a questionnaire that was completed at the end of their participation. The questionnaire is from the perspective of the participants' family and of the service coordinator in which we're looking at barriers to accessing regional center services."
No	2	"Not for this particular year. The year prior we did."

Table 13. SAE Project Managers' responses to the most significant challenges in implementing their SAE grant project

Coding Structure	Frequency	Illustrative Quotes
Lack of trust and relationship building with families and communities	6	"When we look at it specifically with ethnicities, there are different ethnicities who value the relationship piece, that is what builds trust. It often is easy to look at it through our American lens or our White Caucasian lens, depending on the scenario, where if I went to a regional center, I would never think about the importance of, "I need to build trust with them before." I would talk about what my service needs are and I would see if they could meet my service needs. Trust building and relationship building is huge, and I don't think that we have prioritized enough of that." "There were families that were very much afraid to step forward and have their name, much less their child's name, on taking any kind of public assistance. They didn't understand the regional center is not a government entity. Our funding is federal and state, so it's a gray line there anyway, so very much afraid to have their name recorded when ICE was running around and scaring people."
Lack of departmental coordination and buy-in	6	"It's trying to get all the other departments on board. For example, we were trying to engage a number of service coordinators and managers in motivational interviewing training, but there were all these other competing training demands. They're learning self-determination. They're learning all the new directives out from DDS to make space on their calendar to also do that." "When we look at just SAE grants, for regional centers, especially a smaller regional center like [ours]…our social work staff carry caseloads of 90-plus individuals to the point where when we send out resources around any type of special activity, SAE activities, whether it's internal, or CBOs, etc., we have had staff ask, "Can our cultural diversity specialist just send this out?" It ends up being one person to, say, 5,000 people versus all the case managers that handle 5,000 people…. Having the staff time capacity to develop those relationships through a different department, say, mine, as well as social work not having the time to help with passing on that relationship, so to speak, is a huge challenge."

Table 13 (continued). SAE Project Managers' responses to the most significant challenges in implementing their SAE grant project

Coding Structure	Frequency	Illustrative Quotes
Lack of guidance regarding deliverables, expectations, and partnerships	4	"The lack of support, training, guidance. It feels to me that a lot of that is decided and then everything else is an afterthought. It shouldn't be an afterthought. We can look at these. What happened with that is that, chances of success are low. When you don't provide the resources, the education, the guidance to regional centers and staff how to move forward with this project."
COVID-related	3	"COVID turned everything upside down. The screening schedule had to stop. We thought, "Oh, OK, in a couple months we'll be past that."
Lack of adequate resources (mainly lack of staff and funding)	3	"The second one is that when they made this program, they didn't consider the ratio to our population. We should mirror the population we serve. We did not with the amount of navigators that we took on."
Complex systems and processes that contribute additional challenges	3	"It's a difficult system to navigate, first to get into self-determination, and then to be able to qualify for it, and then to manage and facilitate your budget. A lot of the families have said, our lower-income families, they don't have the time to manage a budget. They're just basically subsistence level, trying to manage their lives." "Computer and just literacy…especially during COVID, those families all of a sudden had to jump onto the digital world. It's just like, what do you do when you don't have Internet services and you need behavioral services that are being provided via Zoom?"

Table 14. SAE Project Managers' responses to whether or not their SAE project worked directly with persons with IDD and their family members from racially, ethnically, culturally and linguistically diverse backgrounds

i. If yes, what barriers were encountered in these efforts?

Coding Structure	Frequency	Illustrative Quotes
Yes	14	
Barriers encountered		
Inadequate resources to address families' needs	3	"When the family's ready to receive services, the therapist that provides services might not be the one who can speak their native language. That's created a barrier, especially those that rare language."
Insufficient time to build trust and relationships with families and communities	3	"When you have grant-based projects and then that grant-based project, and all the planning that you have developed and that you have established and all that connection that you have established with the community goes away in two years, I don't think that helps trust. It's like, "OK, here we have this work, and now it's gone." It's important to identify the things that are really needed that have to be long-term and not just the grant. I see that these projects appear and disappear, and then the communities feel lost. Wait a minute. We've had these services before. Now you don't have it anymore. They don't understand why it's gone"
Limited engagement from families due to personal circumstances	3	"Another one was that families that we intentionally felt could benefit from the transportation grant and go to a conference or attend a set of workshops with the transportation grant. They either didn't want it, because they didn't feel that they had the time for it. They didn't have respite in place to maybe take care of their kiddo while they were attending the workshops."
Stigma related to needing care	2	"I encountered some of the situation where the family's in the denial stage, that they didn't want to get service early. They didn't want to think that the child has disability or developmental delay."

Table 15. SAE Project Managers' responses to the most significant outcome from their SAE project in terms of disparity reductions

Coding Structure	Frequency	Illustrative Quotes
Increased POS and number of people served	6	"Our purchase of service expenditures have increased every year since the project's implementation, certainly for the fiscal years that you're looking at. Our purchase of service expenditures increased by 113 percent for the first fiscal year and 213 percent the second year. 354 percent the third year. We've been shockingly successful in reaching that outcome." "When I had those four service coordinators, they were in charge not only of doing outreach and providing information to the community, and visiting all these individuals that work with babies in the community, but also following up with our vendor's list to, "Hey, I see that Johnny has a Purchase of Services for 10 sessions." The month of September, you only provided 4. What happened?"
Built trust with families and increased community engagement and partnerships	5	"I don't think it made the biggest difference in POS dollars directly, but it built more trust with us in the families and the CBO. It helped create a bit of a bridge, but it brought more opportunities for different programs."
Increased families' knowledge about RC services and service navigation through information sharing and additional supports	5	"Our online virtual trainings…we're getting a lot of feedback about, for example…the best one for me is, "I didn't even know the service existed." Certainly, planting seeds about expanding individuals' knowledge of different service options that they could access. The other one is, 'I didn't know that I could appeal a service.'" "The conferences served a variety of topics. So, to me that in just says that the families were exposed to this information."
System improvement	2	"The creation and establishment of the specialized 1 to 40 caseloads within the regional center system designed to target and serve low to no POS utilization clients of diverse backgrounds."

Table 16. SAE Project Managers' responses to the types of data collected to document disparities reductions

Coding Structure	Frequency	Illustrative Quotes
POS and expenditure reports	6	"Purchase of services. I look at their purchase of services. When a person comes in, I go into our system and see what services they're receiving, how much in total expenditures they're receiving. I looked at that information one year prior to entering the project, so an average of over a year." "A lot of the information we gather is what we're able to extract from our system…Here, you have based on the way the data shows on expenditure due to ethnicities. All this data that we put into our reports is how we're able to study what we're looking at." "Still looking at it quantitatively, obviously, it was our purchase of service data. Did we have a significant reduction in the numbers of purchase of service, difference in dollars, and spending?"
Evaluation surveys and questionnaires	5	"The type of data that we collected was around interest and satisfaction with [our project], the individual topics as well as things like keynotes, whether it was something that related to those needs, numbers of people that attended." "I know there was a satisfaction survey, there was a needs assessment survey."
Anecdotal feedback	2	"Service coordinators would also document whenever they had a conversation with the Promotora. It's a lot more narrative than numbers."

Table 17. SAE Project Managers' responses to data collection and analysis efforts on SAE project findings in the following categories

Coding Structure	Frequency	Illustrative Quotes
Race		
Yes	13	"During the intake process, the family have to fill out the application and thus identify their race, their ethnicity, the language that they spoken, primary at home. That's how we capture the data."
No	1	
Ethnicity		
Yes	13	
No	1	
Languages Spoken		
Yes	14	"Yes. It is a little intensive when I do all this data gathering, and including, for example, how many individuals are in the community? What is the percentage of individuals of, let's say, Hispanics?"
No	1	"No, because it was all offered in Spanish."
Geographic Locale		
Yes	12	"We did look at the geographical location because we wanted to determine how far they were driving."
No	2	"No. [Name of county] was only for [name of county] families. [Name of county] was only for [name of county] families. We didn't do a smaller geographic location."
Not sure	1	
Socioeconomic Status		
Yes	3	
No	10	"No, because our program is not income based. We do not collect that. We only collect the income information when the family asking for financial support, like helping with a co-payment, co-deductible. We do collect that. Other than that, we don't."
Not sure	1	
Other Factors		
Age	5	"We do have the information by age too."
Living arrangement	3	
Disability/diagnosis	2	
Cultural match	1	"The other thing we looked at is cultural match between case manager and recipient, because that's a meaningful statistic."
Referrals	1	"Referrals. These kids are not just referred to regional center. Some of them need dentist. Sometimes it's a parent who needs some mental health support. We track for each screening the number and the type of referrals that are made. They're not only referred to regional center but also to the school district as well depending on the age."

Figure 2. SAE Project Managers' responses to data collection and analyses efforts in the abovementioned categories
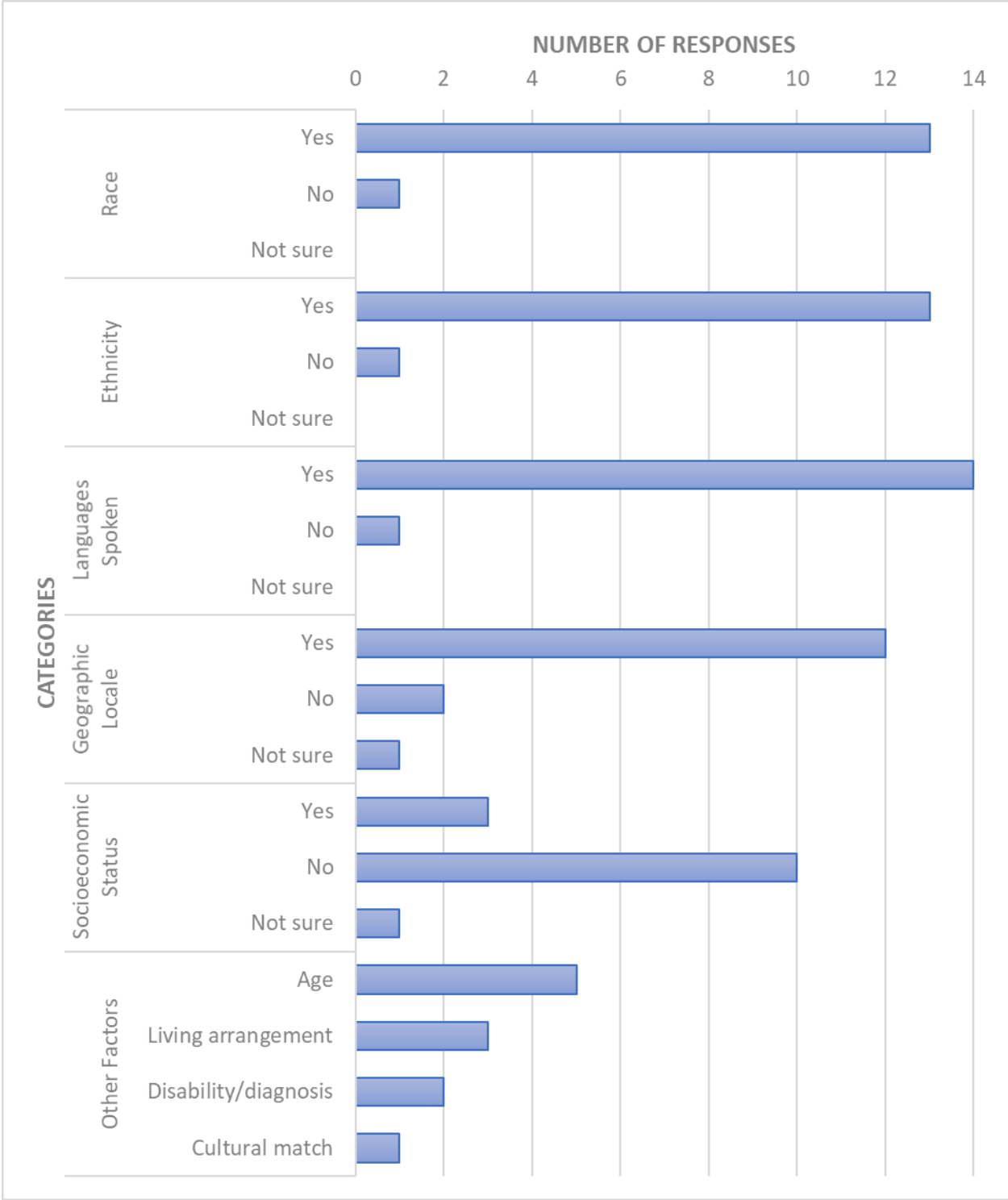
Table 18. SAE Project Managers' responses to their current capacity for collecting, analyzing and reporting on disparities data for the SAE program

Coding Structure	Frequency	Illustrative Quotes
Low	9	"I would have to say low capacity, because I think that this system, it's hard to gather data." "So now that you ask that, I'm honestly unaware if our regional center has the capacity to do that. The reports that I've seen have usually been generated by outside organizations or provided to us by DDS or provided by community-based organizations like the Voices United, for example, that just released a report this week highlighting some disparities among regional centers."
Moderate	5	"I would say moderate. I am usually the one that's responsible for that. I would say moderate."
High	3	"Specifically speaking about the grant that we wrote for [this project], it was a pretty high capacity."

Table 19. SAE Project Managers' responses to whether or not their SAE project led to an increase in the following areas

Coding Structure	Frequency	Illustrative Quotes
Availability of supports and services		
Yes	11	"The availability, they were more aware, thanks to the navigator program and then culturally appropriate programs as well. The families were more aware of these because these people were already embedded in the community as it were."
No	2	
Accessibility of supports and services		
Yes	9	"I think it allowed families to gain accessibility for sure."
No	3	"Accessibility, as always, it's probably no because we can't control accessibility based on a geographical location."
Not sure	1	"I'm not sure that it's quite to the point that it will help increase [accessibility of] respite, housing, or other types of services as much. I think is still in the building trust phase, if you will."
Acceptability of supports and services		
Yes	10	"It truly did help some families better understand what type of services are available through our regional center. Bring much more of an open mindedness to how to accept those services."
No	1	
Not sure	2	
Quality of supports and services		
Yes	4	"I would say yes for the quality of support and services as well because all of the therapists are licensed, so they [are] professional."
No	7	"I'm going to say no because I really don't see us be able to control specifically the quality."
Not sure	4	
Utilization of supports and services		
Yes	8	"Yes. I think utilization had increased, thanks to the navigator program."
No	3	"Utilization, I'm going to say no because we did not see a decrease in the disparity."
Not sure	2	"I would say, also, I don't know because we don't collect it, or we haven't been keeping track of those specifically."

Figure 3. SAE Project Managers' responses to their SAE projects' impact/increase in the supports and services of the on the abovementioned categories
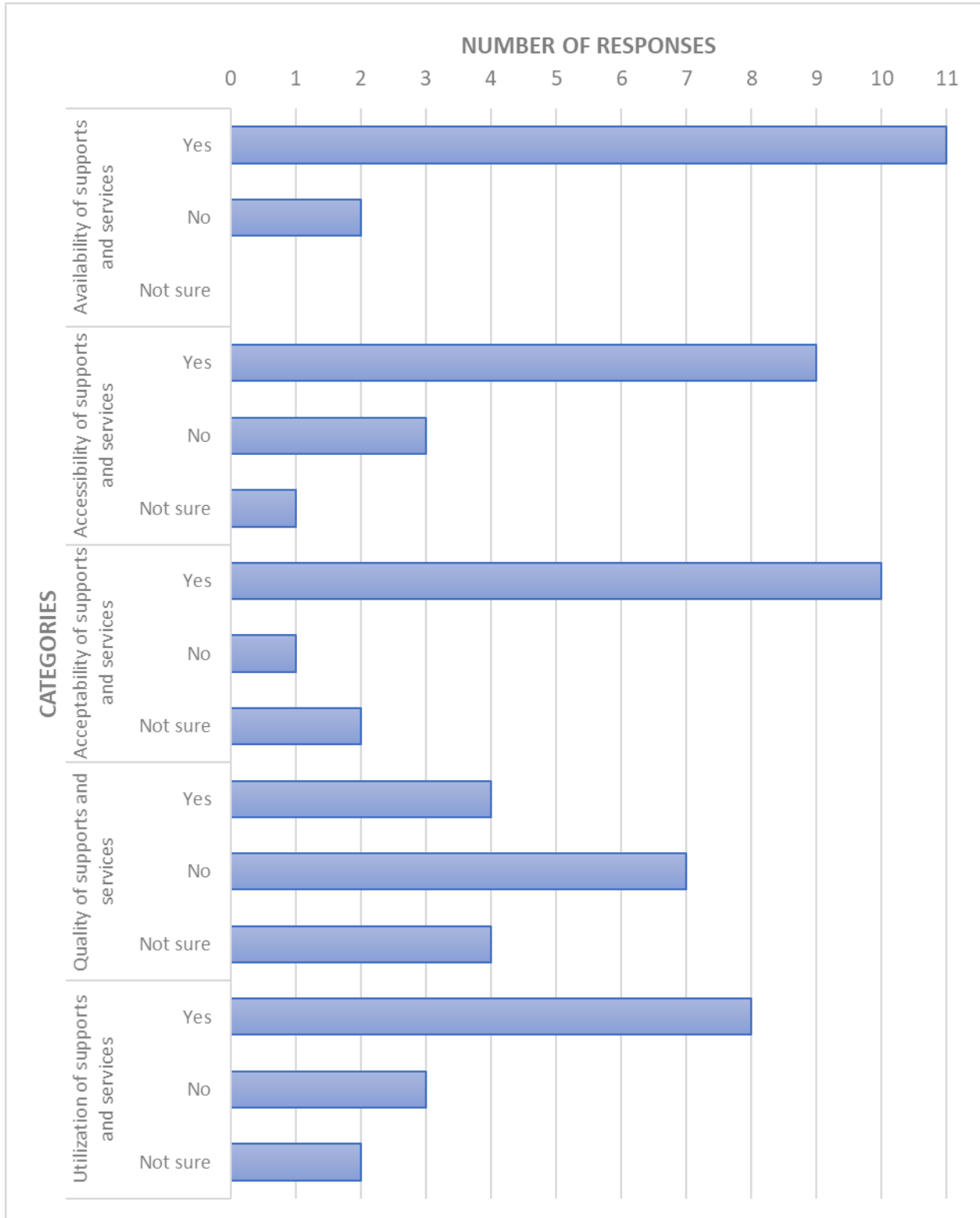
Table 20. SAE Project Managers' responses to the strategies used with their SAE grant activities to reach potential individuals with IDD and their families that are unknown or not receiving services through the Regional Center

Coding Structure	Frequency	Illustrative Quotes
Focused outreach to underrepresented and underserved communities	8	"We do a ton of outreach. Community engagement department does a lot of outreach and we target certain school districts and certain community events for that purpose, to kind of meet families where they're at or where they gather. The other thing was when, like let's say, a purchase of service meeting was about to come about, certain workshop trainings…Not only do we use social media, which is very highly active, and we have a high connection to our community with that that source." "We also mailed…There was a couple of different occasions that we mailed flyers about certain activities and workshops and trainings conferences with IPPs. So as the IPPs were going out for like two months we would mail certain things out. So that was another way. I've always been a stickler about mail option to not go away because a lot of our families, that's the only way that they receive information." "Our strength in [this regional center] is a legendary good relationship with non-profit organizations who are there in the community all the time serving these populations. They know the people. They know who's been left out. We have worked diligently with them. We have strengthened that connection with them. It is through them that we have succeeded in our projects. "
Family training and education (including peer-to-peer education)	4	"So, the idea was to train family members to then go out and spread the word among their network as well as training…it was giving informational materials to family members to identify, to help them kind of reach out to their circles, also training service coordinators in motivational interviewing techniques and how to get around bias in interviewing."
Not applicable	3	"For our project. It's not applicable because we only work with families that are already in the reduced [caseloads] system."

Table 21. SAE Project Managers' responses to the importance of the grant program to their Regional Center's efforts to decrease disparities among persons with IDD across racial, ethnic and linguistic groups

Coding Structure	Frequency	Illustrative Quotes
Very important	8	"Very important. The reason why is because this is extra money that is not allocated in the budget and, like I say, is makes my dreams come true. That can provide and do more specific things that we don't have a budget for."
Important (but improvements are still needed)	6	"It's important in the sense that it almost…To me, these grants allow to have pilot projects. Again, once we identify pilot projects that are successful, we need to be able to fund them, to have ongoing funding." "The projects are very good for our families. We salute the effort, and we encourage DDS to continue doing that. In terms of reducing disparities, it appears that those projects are not necessarily producing the change that we were hoping that would happen in a short period of time."
Difficult to ascertain (often due to competition for funding)	2	"When you ask, how important are these grants, it's difficult to answer, because, at least for our regional center, it does appear that these grants are really effective in helping us to address systemic issues. Having said that, when any funds are available, we're going to want to draw some of them down for our regional center because it's such a massive problem that we want to try to get any available funds. But for these grants, regional centers are competing again, not for profit organizations as well, and that creates competition where there should be collaboration, and it really pits profit organizations against the regional center, because what we see, at least in our catchment area, is that these independent non-profit organizations will say…their justification for funding is needed is because the regional center is not getting things done. That's valid, clearly. But it doesn't set us up to tackle this together. I guess that's what I would say. That's just my sort of viewpoint."

Appendix C

Qualitative Coding Tables: Listening Sessions with Families of Persons with IDD

Results

Listed below are the coding structure and illustrative comments that emerged across all the listening sessions convened with the families of persons who experience Intellectual and Developmental Disabilities. (n=70). Tables 1 – 9 present the coding structure of participants who indicated that they were SAE grant family participants (n=32) with frequencies and selected delineative quotes. Table 10 – 18 present the coding structure of participants who were family recipients of Regional Center (RC) services (n=38) with frequencies and selected delineative quotes. It is uncertain if some of those designated as family recipients of Regional Center were also SAE grantees as they were not presented with an opportunity to indicate that affiliation in initial recruitment efforts.

Coding Structure: SAE Grant Family Participants (n=32)

Table 1.SAE Grant Family participants' responses to whether the supports and services received were available when they or their family needed them (n=32)

Responses indicated that services were *not always available* when families needed them. Many participants experienced long wait times for services, or were unable to access them at all due to delays. They emphasized the importance of timely access, as delays can have a significant impact on the lives of those in need of services. Additionally, staffing challenges surfaced as an issue as families highlighted the difficulty of finding qualified professionals to provide services, leading to longer wait times and unmet needs. Lastly, a few participants also indicated that due to misinformation about resources available, they felt that they did not qualify for services. This created a barrier, especially for those who were less likely to challenge a governmental system or push for services they felt they deserved.

Coding Structure	Frequency	Illustrative Quotes
No, services were not available when needed Denial by delay was a term that recurred multiple times	13	"No. It was very difficult finding qualified professionals available to evaluate my son. This was to get the diagnostic evaluation started and begin service navigation." "Delaying is denying and misinformation for immigrant communities about resources available can create an insurmountable barrier for access." "No, they weren't – In fact we were made to feel like we didn't really qualify for services. Cultural shame and guilt also contributed to us not pushing."

Table 1 (continued). SAE Grant Family participants' responses to whether the supports and services received were available when they or their family needed them (n=32)

Coding Structure	Frequency	Illustrative Quotes
Somewhat, depending on variables such as waitlists, vendor availability, processing times etc.	9	"Somewhat due to staff shortages, there is a wait to receive many services" "Because there are so many different services, the answer is yes and no. Yes, some of the services were definitely available immediately, but then no, some of them were not, for various reasons." "There are some resources that I've received that have fallen right in line with what my son has needed, but there are others that it's still a challenge and I'm in the process of working that out. Hopefully that can happen soon."
Yes, services were available when needed	8	"Yes, the services were open and available. Not having a long wait time helps families accept services easier and without feeling like they are wasting their time" "The answer is yes. I received Adult Day program services and also respite services. They were available when I needed them."

Table 2. SAE Grant Family participants' responses to whether the supports and services received were available in their preferred language (n=32)

The majority of respondents indicated that their preferred language was *available*, however most participants stated that English was their preferred language and did not view it as a barrier. A few participants indicated that they were not able to obtain providers who spoke their language, or that when translation or interpretation were provided it or they did not capture important lingual and cultural nuances.

Coding Structure	Frequency	Illustrative Quotes
Yes	19	"Yes, my family speaks English and language was not a barrier." "Yes, but it was full of jargon." "Yes, but my preferred language is English, so that's not hard to get."
No	6	"There are no service providers in my language. Culturally it is important to have providers who speak the same language as me." "Even if it was the interpretation of the service was hard to understand (there was) cultural insensitivity"
Sometimes	2	"Yes and no. Yes, the language option was available, but no, there were a limited number of staff who spoke our language, leading to delays in services."

Table 3. SAE Grant Family participants' responses to whether the supports and services received were available in ways that took their family's culture into consideration (n=32)

Respondents indicated that there is a lack of cultural competency. Data indicated there is a need for more cultural competence and sensitivity to ensure that families can receive supports and services that take their culture and values into account.

Coding Structure	Frequency	Illustrative Quotes
No	21	"No. This is one of the biggest barriers in our community. "No. Regional Centers are more concerned with gatekeeping services rather than considering our culture or needs. If culture, language, needs were taken into consideration, families would have access to what they need and cut down on the amount of time/effort" "There aren't any when I think about Regional Center, there isn't anyone in our Regional Center that looks like us to give or to provide services. That's still a present challenge… I just think that people are just trying to do their job and relate as best to my children as possible, and they're not thinking about our cultures. They're just thinking about how do I get this child to respond to me?"
Somewhat	4	"This is a very loaded question, I think that yes because my family can change their schedules and has understanding of what the services are however, working with indigenous families we need more flexibility and cultural awareness." "50-50. Some organizations or staff were culturally competent while others only spoke the Korean language without knowing the right approach."
Yes - mostly	4	"Yes, family culture and values need to be taken into account for the application to appropriate resources." "Now, we're good because we have people on board who respect the way our point of view and the way our life is."

Table 4. SAE Grant Family participants' responses to whether the supports and services received were accessible (easy to get to or find) when they needed them (n=32)

Respondents indicated that there are challenges in the accessibility of supports and services. Participants stated that service coordinators (SCs) are often gatekeepers of services, and do not communicate clearly about what types of services are available to families. Many families noted that they have to advocate and put up a fight in order to receive supports and services, adding a barrier to families. This is particularly the case for families who are not able to advocate for themselves consistently. Participants noted that, even when services were approved, they were met with lack of providers or vendors in the area, leading to a delay or a pause in services and supports. Additionally, some families noted that it was difficult to navigate the DDS system and understand the processes, especially if their SC or case manager was not knowledgeable and/or helpful.

Coding Structure	Frequency	Illustrative Quotes
Not accessible	17	"No, RC maintains a culture of NO. You need to fight for services RCs are disconnected from communities they support." "No, it is difficult to get services and often times our family had to fight and advocate for ourselves to get services. We were able to do that as fluent bilingual speakers. I'd imagine families without English have a harder time." "No. I had to go through a cycle of request and denial until I became educated on my parental rights and my son's rights." "I was told that whatever my son needed, he could get from the school district. It wasn't until recently that I learned that there were actually services that my son could actually benefit from but we weren't really informed of them." "No, vendors are not person centric and RC coordinators say their hands are tied because of limited vendored providers."
Somewhat accessible	6	"Depends on the knowledge of the case manager. Easy access to supports and services is so important. Otherwise, people don't know where to look and will not get the services they need." "I would have to say yes and no. It was accessible for the Adult Day program. However, when I requested respite, it was like I had to put the reason I needed the respite. I was told the supervisor had to approve it. I sent several emails. There was no response. Then I just continuously followed up. Finally, I was offered a few hours."

Table 4 (continued). SAE Grant Family participants' responses to whether the supports and services received were accessible (easy to get to or find) when they needed them (n=32)

Coding Structure	Frequency	Illustrative Quotes
Accessible	5	"Yes, because I was familiar with the Regional Center system. The challenge was lack of providers/vendors and staff." "I would have to say the answer is yes. The service that we received was working with a nutritionist that dealt with issues with kids who are Autistic, restricted diet type things. We accessed the person through Zoom meetings and we were able to email, phone, or contact her by phone. I would say it was accessible. It sounds like in this specialized area, she was the only person available."

Table 5. SAE Grant Family participants' responses regarding the acceptability of supports and services they received (n=32)

Respondents indicated that supports and services ranged from *somewhat acceptable* to *acceptable*. However, families stated that they had to constantly advocate to receive supports and services, highlighting the difficult processes and barriers. It is worth noting that many respondents mentioned the Self-Determination Program (SDP) as being *very acceptable* because it allowed individuals and families to take control and make decisions about the supports and services they were receiving.

Coding Structure	Frequency	Illustrative Quotes
Somewhat acceptable	12	"Some were better than others. But a lot of the services, we had to fight to get a reasonable amount of support. I've seen my families give up because they feel it is too hard to receive services. This ends up hurting the person with IDD the most." "Somewhat acceptable…Because, again, when I mentioned that they provide you the vendors that they're going to allow you to work with...Again, you don't know what you don't know. I had to go through a couple of vendors because they didn't work or they were doing things that I felt were suspect. For me, that was really it. They were providing some services. Again, because I was not as informed at that time, but now looking in hindsight it's like that should not have happened. Some of the services actually helped a little bit, but I would say it should have helped more."
Acceptable *But often with a lot of personal effort*	7	"Once we had overcome staffing barriers, we were happy with the service when it started. But I'm always worried the provider staff will change again." "I would say acceptable because [name of son withheld for anonymity] is new. We're still getting him lined out with everything because he's only been a client maybe nine months…they've been acceptable." "This is all I know...I don't know if the services should be different or better. As far as I know, they've been acceptable."
Not acceptable	3	"Not acceptable that I had to argue back and forth for months before a support was approved. The client suffers during this period and makes it very challenging and draining for the parent." "The services were provided but the staff and providers were not competent. Self-determination has given us the option to find our own providers so it is better now"

Table 6. SAE Grant Family participants' responses regarding the quality of the supports and services they received (n=32)

Respondents indicated that the quality of supports and services *varied* greatly, with the largest percentage rating them as *fair*. They also highlighted a lack of consistency in vendors and qualified professionals providing services. Comments suggested that families viewed their service use as taking what they could get, but they would prefer high quality supports and services more consistently.

Coding Structure	Frequency	Illustrative Quotes
Fair	12	"I would say that they were fair. That's all-encompassing." "Fair because anything and everything helps but there are no set standards and accountability." "Fair. My husband complains. He says, 'I feel like you do their job and you don't get paid for it.' Too often, I will contact the coordinator and tell them all these stuff that I found. They're like, 'Oh, wow. That's interesting. What was that? Where was that at?' They'll take down notes and everything. It's like, 'OK. Now what do you have for me?' It [the services] is just [rated] fair."
Varies Depends on various factors such as vendor, staffing, etc.	7	"The provider is a family member so they are familiar with our situation and have cared for our daughter frequently. Providers must be competent. We have had many non-family members who were ABSOLUTELY incompetent." "It varies depending on the person we're interacting with. It is a range of quality." "Then as far as vendors are concerned, that varies. My son received a lot of different services, so it's different from vendor to vendor. If I could average it through, I would say it was fair, and fair is not good. Fair is not good."
Good	4	"Because it was so tough to start working with the provider due to staffing issues, I don't know what "excellent" might look like. We had to go with the first provider that could get staffing."
Excellent	3	"I'll say excellent now that I've moved the boys to the [name of program withheld for anonymity]."
Poor	2	"It's a struggle to get these services approved by RC first. Once they decide to approve the support, it's a struggle to get the adequate personnel or a schedule that works for everyone. The way the system is set up right now fails at every turn."

Table 7. SAE Grant Family participants' responses regarding the usefulness of the supports and services they received (n=32)

Families indicated that the services and supports they received ranged from *useful* to *very useful*. However, to qualify for and obtain services, they had to maneuver through complex processes and advocate for themselves. Additionally, some families noted that although the services were *useful*, they were limited, which created an additional barrier (need vs access). Overall, families found supports and services *useful*, but suggested improvements in more timely access, greater diversity of services, and increased cooperation of SCs and case managers.

Coding Structure	Frequency	Illustrative Quotes
Useful	11	"Useful because anything you receive helps but there are not enough services that are needed able to be accessed. Need vs access." "The services are useful but the quality is not always adequate. We have to give more importance to the quality of these services because the utility is directly associated with the customer's need." "Useful because I love his behavioral therapist." "Regional Center, I would say useful, but that's more on me than on them. I would see what was available, make sure I stayed in tune with information that was being put out. For me, I would say useful."
Very useful	7	"Very, the therapy services are with a group of kids and being social has helped my godson so much Finding community is so important and the servicer was great." "It gave my child the support she needed and our family the reprieve during the pandemic - however, staff turnover with the traditional vendor was high self-determination helped us a great deal for quality of life for our child and us! choice, freedom and consistency played a huge role to support us." "When I have respite, it's very useful. Being able to take advantage of having some time to just do what you would like to do or need to do or want to do is a luxury for a mom who's having to do everything, and not really having space to be free to do that. Definitively, it's very useful."

Table 7 (continued). SAE Grant Family participants' responses regarding the usefulness of the supports and services they received (n=32)

Coding Structure	Frequency	Illustrative Quotes
Somewhat useful	5	"Once you received a service it makes a difference but getting to that point is extremely challenging. Complex system to navigate." "Somewhat useful on their side because a lot of times, I didn't really understand what they were doing. They sometimes didn't share or...This is what made it a little bit more difficult. Oftentimes, the people they would send out to work were new. They may have been in college, and that's great, but may not have been qualified at the highest level possible."
Not useful at all	2	"I've had two annual meetings with my case manager and she has not fixed, has not followed up, and seems fine with me not receiving services yet." "Up until now, the majority have been not at all useful."
Varies	2	"Varies, some supports were awesome, just what my son needed. others felt like a waste of time."

Table 8. SAE Grant Family participants' responses to whether they would recommend the supports and services provided through Regional Centers to another family (n=32)

Despite the challenges and difficulties associated with receiving supports and services, the majority of respondents reported that they would still recommend RCs to other families. Families stated that RCs are a necessary resource and provide valuable services. However, respondents emphasized that in order to access services successfully, families must understand the policies, and timelines of RCs.

Coding Structure	Frequency	Illustrative Quotes
Yes	17	"Yes, and only because we need the support as parents and it is out there - it is very overwhelming otherwise - and we push for elf-determination A family is overwhelmed with caring and supporting their individual - the systemic supports go a long way to relieve the pressure and stress." "Yes, but with a warning label. Make sure to be aware of the trends, policies, and true timelines with your RC and be an active participant." "Yes, because as imperfect as the services and RCs are, no other agency in the state provides what they do. It's a must for families to be connected to them. But much improvement is needed." "Yes. Especially now that the Regional Center has gone into the Self-Determination Program, and especially now that I am learning that your child could be getting a lot more, you're just not requesting the right things, and you're not asking and you're not utilizing the Regional Center to the full potential that is there." "Yes, I would because something is better than nothing. Then with especially this community that we have, once we start telling each other what is available, then other people can find ways to get access to them." "Not a fair question. If you are thirsty would you not drink water if available. Need"
No	3	"I would NOT recommend using the RC system. However, it's all we have. It's too overwhelming and stressful to access anything from the RC." "No, because they don't actually connect you to the services they approve you for...it is needlessly complex and their staff are not helpful my case manager does not know what an NPS is, does not know about services, and has no idea how to connect me to them"

Table 9. SAE Grant Family participants' recommendations to improve DDS supports and services for persons with developmental disabilities (n=32)

According to respondents there are several areas that need improvement. These include increasing staff training, changing the culture of the organization so that staff see their role as service providers and not "gatekeepers of funds and services", reducing caseloads, and making services consistent across RCs. Several of the suggestions are aimed at development of a person-centered system that is transparent, accountable, and provides equitable opportunities. Families also recommended that, DDS will increase access to resources, provide more individualized support, improve communication between providers and families, increase collaboration with families, and ensure that services are culturally and linguistically competent.

Coding Structure	Frequency	Illustrative Quotes
Be Transparent regarding services and supports offered	11	"I would have to say probably improving information. It sounds like it depends on which Regional Center you're with, which service coordinator you're with to even know what services are available to your child. If there was more information for parents, maybe a website or part of a website where we could find out. Instead of going long periods of time without something then accidently hearing something from someone else. Like, "Wait a minute. That's offered? That's an option?" (My recommendation) would be more information." "More transparency. I've said this to multiple Regional Center employees that I'm tired of hearing them say that (a support or service is) not available to my son right now because he's not in that age group. Let me know exactly what's available for his age group. Every time I get a new SC, I hear the same thing. I don't know if that's what they say when they don't know, but I'm tired of hearing it. You need a new lie. Just show me what is available for that age group then, and then I'll know what he can get. I won't be wasting my time talking to you all the time and asking for stuff that I see that he would benefit from…"
Increase staff Training.	5	"I believe that definitely a lot of people come into these roles with DDS and other services, but they're not adequately trained. "Retrain all RC staff. The mentality of gatekeeping has to change. The money for these services does not come out of their pockets. Staff who have been around for years just will never change that mentality. New staff need to be trained by neutral people."

Coding Structure	Frequency	Illustrative Quotes
Focus outreach to educate and orient parents about the process of obtaining supports and services	5	"Invest in parent support and navigator programs… New parents and adult clients need patience and time." "I would recommend them creating an outreach committee of some sort, maybe having an outreach committee in every Regional Center. I like what [name of fellow participant]] said about having some information (at) the schools… if that outreach committee could reach out to public schools or schools in the area so that children who are receiving special education services, could be introduced to these 12 different entitlements (where, they may say)'Hey, you can get some help for your child social life and community in addition to what you're receiving from your school.' That would have been helpful."
Embed and improve cultural and linguistic sensitivity in supports and services	4	"For us, as a Black community, that means not just focusing on language as the only disparity that exists for me, it shifts at the foundation of it all. It's understanding and helping the different communities at the access points that are relevant to them, and being open enough to receive that information even if it does not look the way that government does things, and encouraging DDS to look outside of the box and do things a little less government based and more community and grassroots based, and bringing us closer together and not them versus us."
Increase oversight and regulation of RCs and DDS' operations	3	"Address the issues at the Regional Centers. There (are) significant inconsistencies and poor oversight. It's absolutely frustrating. Regional Centers seemingly don't answer to anyone. It is so complicated to access services. It's impossible to secure the services. Very poor."
Reduce caseloads and improve case management	3	"Service coordinators simply cannot do the work they are required to do with the current caseloads they carry"

Coding Structure: Family Recipients of Regional Center (RC) Services (n=38)

Table 10. Family recipients of Regional Center (RC) services responses to whether the supports and services received were available when they or their family needed them (n=38)

Responses indicated that services were *somewhat available* when families needed them but were often delayed by various factors such as long waiting and processing times, and vendor related delays. Specifically, respondents often mentioned that there was a significant lag time between discussing the need for services and actually receiving them. This led to family members' frustration, difficulty in obtaining timely support, and a major barrier to supports and services for families who did not have the time and resources to advocate for themselves.

Several participants also indicated that services were *not available* when needed, with some mentioning that communication with Regional Centers was often challenging. On the other hand, a few participants expressed that services were *available*; however, they highlighted the importance of a knowledgeable service coordinator as well as needing to be proactive and prepared to advocate for themselves to access services.

Coding Structure	Frequency	Illustrative Quotes
Somewhat, depending on variables such as waitlists, vendor availability, processing time.	19	"There is such a lag time. You can discuss things at this IPP meeting, quarterly meetings, or whatever, and then there's a lag. A lag meaning months." "Yes and no. I guess it's a matter of the timing. We eventually have gotten the services that we needed, but it was a slow process."
No, services were not available when needed	13	"It's very hard. First of all, it's very hard to communicate with the Regional Center. When you need them, it's very hard to get an answer right away." "When I needed them most, no, they were not available to me." "There were some instances where I felt that I had almost an adversarial relationship with Regional Center."

Table 10 (continued). Family recipients of Regional Center (RC) services responses to whether the supports and services received were available when they or their family needed them (n=38)

Coding Structure	Frequency	Illustrative Quotes
Availability of services is dependent on the service coordinator or what the family accomplishes independently	8	"A lot of services that you access depends on the service coordinator, whether or not they're going to inform you of those services, whether or not they have a relationship with their supervisor, such that it's going to be approved." "I took a lot of ownership. I did not rely on Regional Center very much, aside from the funding. To work with the service provider, I did a lot of that myself because I am a professional and I knew what I was trying to achieve."
Yes, services were available when needed	5	"I'm going to say for my son, most of the time, we had a good service coordinator. I'm going to say he did have his services, but only when we're requesting additional hours, a respite, or any type of service, like a speech therapy or a re-evaluation. Even during the pandemic, he ended up getting a lot of services… It depends on the service coordinator. For him, I'm going to say most of the time, 95 percent, the services were there for him."
No, services were not available when needed	6	"We call it denial by delay. That's pretty much what ends up happening." "When we ask for it, we do use it but the problem is accessing it is very, very difficult. Timeliness. Sometimes, it's years. It's not a matter of months. Sometimes it's a matter of years to be able to access a service."

Table 11. Family recipients of Regional Center (RC) services responses to whether the supports and services received were available in their preferred language (n=38)

The majority of participants expressed that the supports and services were *available in their preferred language*, which was predominantly English, with some participants obtaining services in Spanish. A small number of participants reported that they did not receive services in their preferred language, noting the lack of resources, including written materials, available in Regional Centers. Respondents recommended that DDS ensure language accessibility for recipients who are non-English speakers and/or have limited English proficiency.

Coding Structure	Frequency	Illustrative Quotes
Yes	33	"I would say yes. English is my preferred language. I'm pretty privileged that way. I didn't have language barrier issues." "I'm going to say yes...Mainly English, but sometimes I'll request Spanish."
No	3	"I speak Somali. Even though I speak English, I haven't received any services in the language that I speak. I haven't seen anything in writing. There were a lot of resources available in the Regional Center at the time, but the only thing that I've seen it was just in English. That's what I mean (when I say) no."

Table 12. Family recipients of Regional Center (RC) services responses to whether the supports and services received were available in ways that took their family's culture into consideration (n=38)

Several participants expressed that their family's culture was *not considered* in the provision of supports and services. Some felt that assumptions were made about their preferences for services and support without consideration of their culture. Participants indicated having to intervene with the services and supports provided to ensure their family's values, and beliefs were respected. On the other hand, some participants indicated that their family's culture was taken into consideration to some extent. Overall, the respondents indicated that there is room for improvement in terms of Regional Centers ensuring providing supports and services in a manner that honors the families' culture.

Coding Structure	Frequency	Illustrative Quotes
No	17	"In the past, my culture, my background was not considered, I feel, because assumptions were made about my parents and what we wanted. I had to intervene because it's a family decision, and it's a family culture, and it's a family value. At times, no, our culture wasn't considered and it was frowned upon…as far as case managers are concerned and the agency that people should be placed in the residential facilities if they have problems. We saw it more as we are family. We will deal with it culturally. The Hispanic community takes care of their folks." "I don't know if it's just because I'm white, but nobody ever asked me any cultural questions. There are lots of different ways that culture is expressed, like your religious culture or your family culture and things like that…Nobody has asked me, "What family support do you have?" They've not ever explored the bigger picture of who we are beyond in that."
Yes - mostly	11	"To the extent that we define those needs, yes." "Regardless of what those are, if they're religious or just a value system that you have that you celebrate Thanksgiving this way or whatever, I'm going to say yes."
Somewhat	3	"That's a yes and no….Our extended family -- cousins, aunts, uncles, big Mexican family -- Everyone's trying to get reorganized in terms of how they're going to help me or help our family or respond, and then when (the) Regional Center says, 'Now is your family helping you?' Yes, but it was a very new thing for them. Yes, the family helps. They would bring me food. I never had to worry about dinner. That was such a big help, but actually being there…this came with the argument of respite. I wanted more respite hours, to hire people who could deal with a lot of the aggression that we were seeing…They [the RC] said, 'No, only 23 hours.'"

Table 13. Family recipients of Regional Center (RC) services responses to whether the supports and services received were accessible (easy to get to or find) when they needed them (n=38)

Majority of participants indicated that services and supports were *not easily accessible*. However, they did report that the pandemic has resulted in improved accessibility due to the shift to online platforms, such as Zoom, for meetings and support.

Coding Structure	Frequency	Illustrative Quotes
Not accessible without independent efforts and self-advocacy	27	"It's very hard because the support from Regional Center is very limited. I have to find my own answer. When you email them, you are lucky if they respond to an email in one week. Some of the emails they never respond. In the past, I tried to call them. You call the Regional Center, you will never find your case manager. Your phone number always goes to their voicemail. The only person you can talk to is (the) officer of the day, and apparently (the) officer of the day can only take messages for you. They cannot answer any specific question because they don't have the answer. They don't have the background. They don't have experience. All they can do is just maybe pass your message to your case manager, but most of time, even the case manager won't respond." "It's very frustrating that you literally have to put yourself on the line and it's costing you your mental health. Because you have to disclose, you have to explain and do diagrams for them, "This is how I'm spending the time. This is how much I'm doing. This is what I need. This is all the medical doctors that are seeing me. This is all the medical doctors that are seeing my child. Does this make sense that you helped me this much?" It just takes months to get through that point. Seriously, sometimes by the time they give you the service, you're already on a different type of crisis because 90 days after things kept on piling up and the pressure boom escalated into a different new level. It's always catching up. It's like you never get the services the way you need it." "In the past, I struggled for a couple of years. It wasn't easy. It wasn't easy at all. I have to do a lot of research and interview and talk to a lot of people to find out about the services, but for sure, I can tell you it was not from the voice of the service coordinator. That's one thing that I can tell you for sure."

Table 13 (continued). Family recipients of Regional Center (RC) services responses to whether the supports and services received were accessible (easy to get to or find) when they needed them (n=38)

Coding Structure	Frequency	Illustrative Quotes
Continued: Not accessible without independent efforts and self-advocacy	27	"I had to do a lot of advocacy, and not just on a personal level, but on a systemic level. I had to get together with other parents from the Regional Center (of the DDS system) where my son belongs so that they would listen to us… I've had to fight, for every service I've had to get, I've had to advocate a lot, and it's been very hard."
Somewhat accessible	12	"I would say somewhat. We had to identify how far was too far for us to travel. How far were we willing to go to get specific pieces of our requests met? In both circumstances, actually, my son has lived in four different placements over the course of his life and none of them have been closer than 25 miles from our home." "Yes and no. There's a lot of bureaucracy. A lot of the things you want, you have to fill out paperwork or there's time involved, so it depends. I found planning ahead, you have to know what you really want to get from the services, then you really got to speak up. Sometimes you got to really speak up. Services aren't being met. You got to let your service coordinator and others know, 'Hey, I need this taken care of. I've been waiting for this to be done.'"
Accessible	7	"I would say that the pandemic has actually been really good for us accessibility-wise because everything's on Zoom these days. Pre-pandemic, that was a challenge just getting to in-person meetings. I'm hoping that it's just the new normal from now on. For the most part, things have been accessible." "Yeah. I would say yes. I wouldn't say easy to find. I wouldn't say easy but they definitely were accommodated. Our requests were acknowledged and our needs were met."

Table 14. Family recipients of Regional Center (RC) services responses regarding the acceptability of supports and services they received (n=38)

Several participants expressed that the services and supports received ranged from *acceptable* to *somewhat acceptable*. Participants especially attributed this acceptability to the increased flexibility under the Self-Determination Program (SDP), which gives families more choice and control. Some participants stated that the services and supports received were *not acceptable*, due to several factors such as lack of staff training, poor communication, delays in responses. Overall, the acceptability of services and supports varied among participants.

Coding Structure	Frequency	Illustrative Quotes
Acceptable *But often with a lot of personal effort*	13	"Currently they are acceptable. They are very well acceptable because for Self-Determination, we have more voice. We have more flexibility…currently, it is acceptable. It is something that we are comfortable with. The kids are happy and they're in the community. They're being supported. The personnel are happy with the hourly rate. They're loyal and they stay long. They have no trouble being flexible with the child or the parent or the schedule." "Once I took a stand, I will say this, that their services…It was hard to cross it to the mountaintop, but once I got there I can say they're acceptable in my case."
Not acceptable	8	"I would say not acceptable. The reason is that there's so much change going on. The Regional Center staff, they're not trained to answer the questions. There is a lack of communication. They don't respond to your phone call. They don't respond to your email quickly." "No, they were not acceptable, and they were not accessible either. I had to bring in an attorney for that."
Somewhat acceptable	11	"I'm going to say somewhat because, at times, they were not appropriate during certain years, and then other times, appropriate or very appropriate. I guess, in the middle, overall." "For me, some were somewhat acceptable, some were acceptable, and many depended on the therapist or the person providing the service, right? So, you have to learn what the service is like to know if they are giving it well or not."

Table 14 (continued). Family recipients of Regional Center (RC) services responses regarding the acceptability of supports and services they received (n=38)

Coding Structure	Frequency	Illustrative Quotes
Very acceptable But often with a lot of personal effort	4	"I had very specific expectations. I did a lot of interviews with providers. I would ask them about their retention rates. I would ask them about their training processes. I would probe deeply before I would accept services from an agency…If I had not had the experience that I did and I just came in cold as a parent, I don't know that I would have the same degree of satisfaction, but I found them very acceptable simply because of the work and effort that I put into making them so."

Table 15. Family recipients of Regional Center (RC) services responses regarding the quality of the supports and services they received (n=38)

Majority of participants indicated that the quality of services *varied* depending on factors such as the vendor, staffing, and the individual service providers. Due to these inconsistencies, families sometimes experienced highly effective service providers and other times those who were ineffective. Participants reported limited choices in service providers, particularly for specialized services. Some respondents also reported that there is a lack of regular monitoring of service quality. However, those that were participating in the Self-Determination Program (SDP) generally reported that the quality of services were *good*.

Coding Structure	Frequency	Illustrative Quotes
Varies Depends on various factors such as vendor, staffing.	17	"I cannot just rate the overall...It's hard. It's very different. Every provider is so different. We have really good providers. Also, we have some really bad where we cannot stand it." "It's all over the map depending on the vendors and who is available. There's just not a ton of people who do behavioral respite. You don't have choices. There's one agency, basically. Then, even within the agency, you hit or miss depending on the provider that you happen to get assigned."
Good	7	"I would say they're good for both kids. Again, but this is due through self-determination. It's also networking with other parents and identifying (an) independent facilitator that is knowledgeable and compatible to the family. That is the key to success within self-determination."
Very good	3	"Overall, I would say they were very good. I know it's hard between good and excellent. I would say very good. To echo a little bit, sometimes you would have some service providers that were not always up to par. I think we as moms hold people to a higher standard [laughs] at times to be able to provide."
Fair	3	"For some services, it was good at times, and for others, not so good. Just as an overall score, I would say fair."
Excellent	3	"I'd have to say it's somewhere in the middle, but if I had to pick between excellent and good, I'd say excellent. I'd say we've been really fortunate and we've had people who have worked with us and taught us, and we've had way more positive than not."

Table 15 (continued). Family recipients of Regional Center (RC) services responses regarding the quality of the supports and services they received (n=38)

Coding Structure	Frequency	Illustrative Quotes
Poor	1	"I would say poor…Because of the five years of struggle that nobody mentioned any type of services until, like I said, I start hearing between the group of moms, not from the Regional Centers. Yes. Now the story is different, but after how many years have to pass for my son to get all these services? How many years of struggle and silence and nobody coming to me in my worst times offering me straight out all these services. Yes, I will say very poor."

Table 16. Family recipients of Regional Center (RC) services responses regarding the usefulness of the supports and services they received (n=38)

Majority of participants acknowledged the usefulness of supports and services provided, with families generally finding them to be *very useful*. Participants emphasized the role of service coordinators in determining usefulness. Self-determination was also highlighted as positively impactful and *useful*, especially in comparison to traditional supports and service. However, some participants expressed concern regarding the high caseloads, lack of expertise, lack of cultural matching for underrepresented communities, and inconsistencies of service coordinators.

Coding Structure	Frequency	Illustrative Quotes
Very useful	23	"Very useful when you have the right service. One thing I found with (the) Regional Center was that it really depended on the service coordinator. Up until now, it really depends on the service coordinator, how informed they are, who their mentors are, how seasoned they are." "I would say useful to very useful, but again, that's a direct function of how specific I was in identifying the supports that I was looking for." "They're very useful in self-determination. In the traditional system, I don't know that they're very useful at all."
Useful	11	"I'd say, for me, the services that we actually receive are great, and the fact that Regional Centers (are)the funder of last resort is super helpful, but also it'd be nice if we didn't have to get denied by everyone else first to get stuff funded." "Yes, they're useful for the past three years because of, again, because of self-determination. In the past it was just like, let's check off the boxes." "Yes, I saw my son's progress, well, he was learning to talk more, I saw progress in his behavior, in his development."

Table 16 (continued). Family recipients of Regional Center (RC) services responses regarding the usefulness of the supports and services they received (n=38)

Coding Structure	Frequency	Illustrative Quotes
Not too useful	4	"With a caseload of a hundred at our Regional Center, they don't have a lot of energy or expertise in doing that matching outside of linguistic matching. That's problematic, specifically for the Black community. I don't know that they're very useful." "In general, services are not useful when you get people in your home and you're trying and everything is a trial. You're trying to see if it works, you're trying to see if it's a good match. I'm a Black woman. There's no services where you can get cultural matching."
Somewhat useful	2	"I'm going to say somewhat useful because some of that stuff, they never vetted and they give you a resource that they never even followed up to see if it really truly is a good resource."

Table 17. Family recipients of Regional Center (RC) services responses to whether they would recommend the supports and services provided through Regional Centers to another family (n=38)

The majority of participants indicated that they would recommend the services offered through Regional Centers to another family, while emphasizing the importance of self-advocacy. A few participants specifically recommended the Self-Determination Program (SDP) over traditional services due to increase autonomy and greater opportunities for individuals to shape their own support systems and services. Overall, while many participants expressed support and encouraged others to access Regional Center services, there were concerns about families' lack of awareness of available services, restrictions imposed by certain Regional Centers, and dissatisfaction with services provided in certain regions.

Coding Structure	Frequency	Illustrative Quotes
Yes While also encouraging families to advocate for themselves	30	"Without a doubt, definitely. I would definitely recommend it. Especially if you're just starting out, it's so important to get these services." "Based on my personal experience, I do recommend [name of Regional Center withheld for anonymity], but I do encourage them to advocate when they feel that there's a need to advocate and not just to settle with a no or no response, just to advocate." "Yes. If you're willing to fight. I reiterate that as well. You have to fight for them and dig to find the services." "Yes, I would. Because the need that our children have, even if the service is very good or very regular, it helps the child, right? It also helps us, because it helps us to understand, right, because we also observe how they provide the services and we continue them at home."
Would recommend self-determination but not traditional services	5	"Yes, I would recommend self-determination. It is work on the parent. It is not easy. It is hard. There's a lot of curves and mountains to climb, but again, I would not go back to traditional services ever. It has been great for the kids, but yes, it is another full-time job for the parent." "If they can get immediately into the Self-Determination Program, then yes. If they're going straight to the traditional, I would say no. I think because it depends on who you are really in the traditional services."

Table 17 (continued). Family recipients of Regional Center (RC) services responses to whether they would recommend the supports and services provided through Regional Centers to another family (n=38)

Coding Structure	Frequency	Illustrative Quotes
No	3	"Based on my personal experience with [name of Regional Center withheld for anonymity], the answer is absolutely no. I would never recommend them to this particular region. There are good Regional Centers, but unfortunately they're not anywhere near where I live." "No, because they don't make you aware of the services that you're qualified for." "The truth is that it is very restrictive…So, we have to use what exactly this Regional Center says is their initial provider, the grouper, so I wouldn't recommend it, not at all."

Table 18. Family recipients of Regional Center (RC) services recommendations to DDS to improve supports and services for persons with developmental disabilities (n=38)

Families provided several recommendations to enhance the effectiveness of supports and services. Participants emphasized the need for transparency in the services and supports offered. They expressed their frustration with limited information and suggested open communication to allow families to make informed choices. Participants also highlighted the importance of comprehensive staff training, particularly for service coordinators, to ensure staff can engage with families effectively. Additionally, participants stressed the need for DDS to listen to families and involve them in the decision-making processes. Participants also called for improved outreach efforts to educate and inform families about available services and supports. There were also other areas of recommendations, including enhanced cultural and linguistic sensitivity, reduced caseloads for service coordinators, establishment of a complaint filing system and/or external monitoring agency, shifting away from traditional service delivery model to more flexible ones such as the Self-Determination Program (SDP), and implanting universal services that are consistent across all Regional Centers. Overall, the recommendations provided highlight the importance of empowering families and centering their needs to lead to more inclusive, responsive, and effective supports and services for individuals with developmental disabilities and their families.

Coding Structure	Frequency	Illustrative Quotes
Be Transparent regarding services and supports offered	11	"They always hide. It's like they've got the menu behind them. It's sort of like, "Could I see the menu of what my choices are?" They've been told to save money or something. Therefore, they're going to limit what they're going to tell you about the services and the codes and everything else." "I would say that they need to stop making everything so secret. Come out and tell us what you can do. Tell us everything that you could possibly help with. I'm not going to ask for it all. I don't have time for it all. I'm really only going to ask for the things that we need. If I don't know what you offer, I don't know what to ask for. They just need to stop making it such a big secret. Tell us everything you've ever done for anybody. Let me see what things are going to work for my kids and help us have a better life, a more fulfilling life, and help them to reach their potential. Don't let me figure it out by talking to other parents."

Table 18 (continued). Family recipients of Regional Center (RC) services responses to the recommendations they would make to the DDS to improve supports and services for persons with developmental disabilities (n=38)

Coding Structure	Frequency	Illustrative Quotes
Increase staff Training	11	"Even service coordinators, they're hired. They get maybe two weeks of training, but they have a curriculum that takes nine months to complete. They're working with parents, and giving direction, and answering questions with two weeks of knowledge. You get the, 'I have to check. I have to check. I have to check.' Half the time they're wrong. I have trained more service coordinators than I have received help from them. I will tell them, 'That is an acceptable service. Please speak to your unit manager because I am 100 percent sure my son does qualify.' I have to guide them through because they're new. They're recently hired. They haven't completed their training. I understand why they don't know, but it's still frustrating as a parent. I think of all those parents who don't have my experience, who don't have my knowledge, who don't understand how to advocate. We think about how they're being brushed aside and not getting what they could really benefit from." "It would be training to Regional Center staff, training to get them out of the checkbox list, checkbox mentality, training for them to think outside the box, to hear the parent as an equal member of the team."
Listen to families and engage them in the planning supports and services	9	"Everyone has tried their best, and at this point, it's time to just listen to parents and listen to people. Let us run the system. We're not heard and we're not seen and we're not understood. I feel understood at [name of Regional Center withheld for anonymity] because they know I will raise a hundred pounds of sand if I'm not." "Listen to your parents more, support your parents more. If a parent is saying this is what they need for their child to succeed in life, to flourish, to be a productive member of society, listen to the parents. Listen, don't make us fight so hard for everything. Some of us have other children as well as out disabled child." "I feel like more parents need to be on the board when they decide. Let's say, with the POS, the purchase of services, when they develop them, when they create them, definitely, they need input from the parents because sometimes they're written in a way that just doesn't reflect the needs of their clients. That's one suggestion."

Table 18 (continued). Family recipients of Regional Center (RC) services responses to the recommendations they would make to the DDS to improve supports and services for persons with developmental disabilities (n=38)

Coding Structure	Frequency	Illustrative Quotes
Focus outreach to educate and orient parents about the process of obtaining supports and services	8	"Give us orientation meetings on the services our child is entitled for or qualifies for. This is what you need to do to get them. If you need an advocate, these are the steps you have to follow. Give us a guide map for every service that they're eligible for and the requirements so that we're not turned down consecutively, because sometimes I receive pamphlets for workshops that are already outdated. We're in May, and you're giving me a pamphlet for April. That workshop is gone…A booklet with services according to age would be great. Those orientation meetings are important on what is IEP? What is Lean? Step-by-step processes. Maybe if you guys could regulate them and check up on how many parents have you helped with what kind of services? Why don't they have these services? To hold them accountable." "I think there needs to be a reach out. There needs to be more community involvement from the Department of Social Services to let people know what is out there on services for the people with disabilities, the children with disabilities. In our area, a lot of people don't know what [name of Regional Center withheld for anonymity] is."

Table 18 (continued). Family recipients of Regional Center (RC) services responses to the recommendations they would make to the DDS to improve supports and services for persons with developmental disabilities (n=38)

Coding Structure	Frequency	Illustrative Quotes

Embed and improve cultural and linguistic sensitivity in supports and services	7	"They need to teach case managers and (the) administration (about) sensitivity to families, to respect family values. It has to come from the top, and it doesn't a lot. To me, that's the number one priority is to be respectful of the families and the parents. It's a very tough job, I know because I was there, but that's what I think it has to be, and sensitivity from the department also." "Even though you think I'm speaking good English, the reality is that if not your own language, you miss many very important issues. Even if they have a reading one, I would take and read each one of them to understand... I give up and I say, 'OK, I don't need even though I know I need it.' Many, in my community, also dismissed it because they don't understand. Social recreation is the same thing. You're asking them and nobody has explained to you in detail in your own language or give you a written language, like in Somali, Swahili, Arabic, or Afghan. They need multiple accessible languages that they can translate so we can access those languages and those services." "Many are afraid (because they are undocumented), others feel grateful, etc. In short, all these factors affect. And they affect how one interacts with the Regional Centers or not. Due to lack of, ignorance, cultural issues, and many other factors that also affect."
Reduce caseload and improve case management	6	"Having better caseloads would allow service coordinators the opportunity to actually get to know families and individuals, so they're not just tossing like, 'Oh, you have this diagnosis. That means, according to our formula, this is the service that I offer.' I see that a lot. You have Autism, you need ABA. You have Down syndrome, you need dance and music. They put you in a category, and if that's not your circumstance, that's not your interest, that's not your child's need, you have to be a parent who understands and can express and identify why something different is more important, or ask the right question and say, 'Don't you have anything that would offer XYZ,' but parents have to lay the trail of breadcrumbs to start service delivery. If there were smaller caseloads with clearer guidelines, I would say, for the case manager as far as how to elicit those pieces of information from parents."

Table 18 (continued). Family recipients of Regional Center (RC) services responses to the recommendations they would make to the DDS to improve supports and services for persons with developmental disabilities (n=38)

Coding Structure	Frequency	Illustrative Quotes

Increase oversight and regulation of RCs and DDS' operations	6	"I would think we need to build up a system for the consumer to file complaints, for some kind of agency to monitor Regional Center's services. Because right now, if parents have difficulty with the Regional Center, they don't know where to file the complaint, which is not right for me. If you have a disagreement with your insurance, you can file a hearing. If you have a disagreement with your IEP, you can file a hearing, too. [But with the Regional Center], If you don't get the support, they're not doing their job to support you, there's no way [to file a complaint] or you don't know which person you should complain to. There's no hotline or no email so you can send an email." "I really do think if you could ask DDS to create external agencies for tough cases so that the family doesn't continue to be abused, harassed, and discriminated against."
Change of service delivery systems so they are less traditional	6	"It would be opening up the mind of a Regional Center people and getting them away from that traditional system that's been in place for the last 50, 80 years. Considering when parents think outside the box through self-determination, 'Hey, this is a possibility. It's never been done. We don't know about it, but hey, this does make sense and let's give it a try.'"
Standardize services and supports across the 21 RCs	5	"I have a couple things. I'd like to see universal services throughout all the Regional Centers. I find that if you get Regional Centers from the [name of areas withheld for anonymity], they're all working from different aspects. Why can't it be universal? No matter what Regional Center you walk through, you're going to get the same resources. If your application's put in or you need this resource, it's going to be generically the same. It's really hard to hear when if you have one [Regional Center] compared to [another Regional Center], where they're like, 'Oh, we can help.' They have resources. They actually have budgets and spend money on the SDP. You go to the [name of area], and it's the complete opposite. You have to fight for it. You don't know the resources. Having something universal throughout all the Regional Centers. That way, everybody is working from the same program, computer system-wise, communication, training. It should just be universal."

Appendix D

Qualitative Coding Tables: Department of Developmental Services Staff
Interviews

Listed below, in tables 1-18, are the coding structure and illustrative comments that

emergedacross all the structured interviews convened with the six DDS staff who participated in the interviews (n=6).

Table 1. Participants' response to how the Department of Developmental Services (DDS) defines equity

Coding structure	Frequency	Illustrative Quotes
No explicit definition across the department	6	"A specific definition of equity is there's not a public definition. I would say that there is an awareness and a mission that is focused on ensuring that individuals in our system are served equitably. Meaning that they have access and the quality of service that others do, who are from different cultures, communities, ethnicities, or race. If I had a definition, I would say that it's encompassing those pieces, which would be both in service and in quality. That individuals have that experience of receiving services in our system in a fair and not just equal way, but actually may need more services than others in order to be served in an equitable way, if that makes sense." "In terms of how the department identifies equity, I'm not quite sure. I personally haven't seen it on their website as a defined term that they use so they want to go by, or anything like that. I do know that, of course, the department is working in equity measures and ensuring them there is equity in everything they're currently doing." "First is with regard to people with intellectual and developmental disabilities. I think there is general awareness of the need to specifically reach equity for them within the context of the other service systems that they navigate. Also, specifically within our system, for the past decade, and more, there's been a growing awareness of differences in how different groups of people within our people we serve may experience our system, our services, or lack of services."

Table 2. Participants' responses to how they would describe DDS's vision to achieve equity

Coding Structure	Frequency	Illustrative Quotes
Definition not clear and inconsistent	3	"I would say there's a shared vision within our division and our team, but that looks completely different. That looks not complete, but it looks different across the other DDS programs, sectors, or branches, and in leadership." "I would describe DDS's vision to achieve equity a little lacking. It can be improved on. The vision itself the DDS has…of course, it has a lot of good elements that we work for or toward, but it seems wordy, in a way not clear."
Ensuring equitable access to services	4	"I think that the vision DDS has is through a great deal of stakeholder family and advocate involvement in system decision-making and development processes or refinement of processes. I think that's a huge component." "My vision would be that we incorporate a culture in our system that is focused on ensuring equitable access and quality services to every individual that not only comes through our door but is trying to get through the door…We do need to dig deeper and to find ways to change the way people think about serving black and brown people, people from different cultures, race. It's not just race and ethnicity. It's also just identity and the treatment of individuals who are houseless."
Ensuring equity system wide and at all levels	2	"Equity meaning diversity at all levels of the system, that can ensure the equity that we're looking for. Having equity in hiring, equity in the people who are providing the services, equity in the places where services are provided, equity at the state level, as far as visions. I would think that the DDS's vision was to create equity throughout the system, that would create this equity within purchase of service. Looking at it holistically, that would then trickle down to getting that equity that we're looking for in the actual numbers."

Table 3. Participants' responses to how they would describe the role of disparities reduction in achieving equity in California's developmental disabilities system

Coding Structure	Frequency	Illustrative Quotes
To help address the needs and preferences of families	4	"For me, I always have to take a step back and say, are families going to make sure that they have a home, food on the table, a job, and transportation to get to their jobs. The other stuff like IDD services, I see it as secondary. How do we as government ensure that we make it accommodating, flexible for them, and less stressful for them, on top of what they're trying to do, the necessities that we take for granted? How do we make it easier for them and less stressful for them to obtain our services?" "Looking at dollars and cents coldly, without any other narrative, I think doesn't tell the full story. I do think when we look at disparity, we also have to look at experience. The way a family is treated, for example, if they come into our system and they are a new early start family. The way they are getting offered services, there's biases behind the way that they are offered the service. For example, they go into a house that doesn't appear to be that clean, or maybe it doesn't appear...maybe they don't offer some of the in-home services that a family might be or might need, because there's a lens that's impacting the way services are offered. If the question is disparities reduction, it requires us to think about services that people need and want for themselves, and our menu may not actually be that. We may not have services that families want to embrace culturally."
To determine how current measures adequately describe disparities	3	"That's a tough one to say because there may always be differences between how different groups of people use services. That may not be a bad thing. The more difficult policy piece is looking at those differences and saying, 'Does this mean that there is a barrier to access or is this a choice?' It could be either." "The answer to that question is disparities are measured in lots of different ways. Our state continues to focus on the dollars and cents than on an individual.... If you purely look at per purchase of service, you have to look at the links between how you get a particular service, and what are the other things that impact how you might access.... there's other pieces that impact how those dollars are utilized."

Table 4. Participants' responses to how they would describe the root causes or factors that contribute to disparities in California's system for person with intellectual and/or developmental disabilities (IDD) and their family members from racially, ethni cally, culturally, and linguistically diverse groups

Coding Structure	Frequency	Illustrative Quotes
Personal circumstances of service recipients	6	"Poverty is a major factor in how people understand our system and may not come to the door, because they're focused on dinner on the table. They're focused on working. Some people aren't choosing an in-home Autism program because mom's working at the restaurant all day." "If you're living in a remote rural community in a tribal nation, you do not have the same transportation access to where that service provider or that school might be"
Lack of cultural and linguistic competence of staff	4	"It lacks cultural awareness in a lot of ways, where it hasn't always been meet someone where they're at. That person needs to meet us where we're at, meaning the system." "I think that the regional center itself causes a lot of the issues and problems in disparities themselves, and that could be attributed to service coordination, that whole team. They are the first point of contact with families and they of course, have their own biases."
The isms	4	"The root cause for me, there's systemic racism built-in healthcare, built in our society. American society is built on, I think it's a part of our system. It's in the fabric of it." "The good old racism, that's just it too, and the fact that we have again diverse communities, communities of color, communities who don't speak English as a first language and struggle with those barriers. Good old racism and systemic racism." "I have a hard time not saying that just ableism, in and of itself, is not a root cause for a lot of the things that are happening in our system. Even though we all like to think we might be progressive, I'm always surprised by the language that people continue to use, the way that people describe the services that they provide. It's just a constant education."

Table 4 (continued). Participants' responses to how they would describe the root causes or factors that contribute to disparities in California's system for person with intellectual and/or developmental disabilities (IDD) and their family members from racially, ethnically, culturally, and linguistically diverse groups

Coding Structure	Frequency	Illustrative Quotes
Complex systems difficult to navigate	3	"The systems we have to navigate are difficult. For our family to navigate any of the government systems, it's just difficult. We understand that families who need our services are going to need other services, such as housing, or navigate law, public safety or education system or health care system, it's difficult." "Our system is difficult to understand. It's difficult to navigate if you're coming from the outside. Having worked in a system for a long time, it's still difficult to someone like me sometimes to understand all the nuances of the system."
Concerns with the Lanterman Act	2	"The fact that we have an old system and it was designed without diversity at the table when they were deciding and designing things. It worked well for a small amount of people, or not a small amount, but a specific type of people per se. Now that we have a diverse program, some of those things that we came up with long time ago don't necessarily fit for everyone, are not culturally appropriate, or is just something that the families not interested in doing."

Table 5. Participants' responses to how they would describe the overall impact of the Service Access and Equity (SAE) grant program in reducing disparities

Coding Structure	Frequency	Illustrative Quotes
Increase in knowledge about RC supports and services	5	"The overall impact in reducing disparities, so far, I think that the connector projects have been able to connect a lot of families to generic and regional center services. In terms of the family education projects, I think that a lot more families have knowledge of the regional center system as a result of those trainings." "I can say to you that many of the programs, their overall impact might be knowledge. That might be one of the key components, so they're even aware of a regional center. Many people have no idea what a regional center is. They think it's a place that you go. They have no idea that even it exists." "In terms of the outreach projects, I believe that they have created bridges in the community with a lot of different groups that may have not been connected or aware of the regional center before. For example, a Native American community, we heard reports that some of the tribal leaders had never heard of the regional center. Now, they do. Now, they know that it's there, and other various communities that we've been able to connect with through the outreach efforts."
Minimal impact	3	"Overall, there has not been much change in looking at the overall numbers. We knew that going into it that it was going to take time. You couldn't implement these programs and then numbers were just going to change magically in 12 months or so." "We often forget we expect so much from regional centers and CBOs, but we don't have anything in place for them…We're expecting them to report or to collect and to do all these things to get those numbers to report back and have these amazing things, but we internally don't have that infrastructure."
Built trust in communities	2	"It's to harness and build those trusting relationships with community organizations. States don't do that very well. They do one or two special days a year, and that's their connection. Our community-based organizations, through the grant program, in the last couple of years have now been our key microphone into communities about what they need."

Table 6. Participants' responses of the extent to which purchase of service expenditures accurately identify disparities between racially, ethnically, and linguistically diverse populations served by DDS

Coding Structure	Frequency	Illustrative Quotes
To some extent and should not be the only measure	5	"It's one source of way, but it's not the only way. What's hard, too, is, again, the data that's collected from regional centers, that's been given to DDS. I always think to myself, 'Are they trained properly to collect the best data?' When I've looked at data before, there's a lot of categories of other or unknown, and that's difficult. I think to myself, like, "Are the regional center staff, who is out there with these families or individuals, are they asking the right question to get the best data to give back to the state?" "I think it definitely highlights disparities between those characteristics. Again, it shouldn't be the sole measure, the POS. It definitely highlights the fact that we haven't met people's needs. It should be taken into account. Why do we have so many people of color without POS? It's not that they don't have needs. It's just that we haven't been able to meet them appropriately. It definitely highlights, the POS, it highlights the disparities that we have in the system."

Table 7. Participants' responses to whether theory of change models were used by DDS to facilitate disparities reduction in the SAE grant program

Coding Structure	Frequency	Illustrative Quotes
Not formally	4	"One that's easiest for people to implement is the idea of, in our system, and probably wider, we have our saying, "Nothing about us without us." There's already an emphasis in our system about reflecting the values of the people who are using the services. One model of change is, 'Oh, if we get enough Spanish-speaking, service coordinators, we'll achieve equity. If we get enough multicultural service coordinators, we'll achieve equity.' All of those, in one way or another, are strategies that DDS and regional centers have used."
Not sure	2	"I'm not exactly sure how theory of change models are being used. I came in when the program was already set up. I'm not sure if there was a logic model, or anything like that."

Table 8. Participants' responses to the extent to which the SAE program was designed to reduce disparities at the following levels

Coding Structure	Frequency	Illustrative Quotes
Individual		
To a great extent	3	"There are aspects of the SAE program that are designed to address disparities at the individual level. The community connector projects, in general, work one-on-one with people to reduce barriers and access services. I think that education projects as well, they work one-on-one with people to, for example, learn self-advocacy skills."
Somewhat	1	"I believe so, from what I understand. I'm sure you know that we weren't necessarily part of the birth of the program, but I would assume that."
Little to none	2	"I think that's an area of growth as a system. Considering really having us, really systematic way to value those voices and respond to those voices I think is an area of growth."
Family		
To a great extent	5	"At the family level, I would say much more successful. Probably 80 to 90 percent of the projects were designed with that in mind."
Little to none	1	"Maybe, little, very little."
Community		
Somewhat	3	"The outreach projects would address some disparity at the community level in terms of some access to information. The translation projects as well. There's also been some nice educational videos that have been available to the public to increase access to education and awareness about disabilities or regional center services, stuff like that."
Not sure	2	"I don't know that it's designed to impact community. Some of the impact has raised, or I should say has built bridges between the community and the department and the Regional Center that weren't there before. That is a by-product of the relationships that we're building with the management of the grant if that makes sense."

Table 8 (continued). Participants' responses to the extent to which the SAE program was designed to reduce disparities at the following levels

Coding Structure	Frequency	Illustrative Quotes
Organizational		
To a great extent	1	"There has been cultural competency and implicit bias training conducted for regional center staff. There was one other thing I wanted to mention that I'm forgetting. Overall, with the addition of the community-based organizations in this program, it's created tons of relationships between the community-based organizations and the regional centers that might not have been there before, either through awareness and people are receiving more referrals through the regional center, or referring to the regional centers through these organizations. I just feel like that the relationships have just been getting stronger."
Somewhat	3	"It was taken into consideration as a general broad vision. Where do we want California's delivery system to go?"
Little to none	2	"Not really. To me, the program was designed specifically -- or from what I see and understand -- targeted to support and reduce disparity for individuals and families."
Systems		
Somewhat	4	"We have seen that. I don't know that the whole program was designed to impact that, but I think it has had some effect on organizational and systems changes. I think that the success of individual programs have made regional centers look a little bit more holistically at their operations. Maybe there was an indirect effect of the initial purpose of the grant program."
Little to none	2	"I'm being realistic. I don't think the grant has that kind of system shift. However, I think our reach to the community has been shifted because of it."

Table 9. Participants' responses to what logic model was used by DDS for disparities reduction at each of the following levels (Individual, family, community, organizational, system)

Coding Structure	Frequency	Illustrative Quotes
Not formally	4	"I think that the strategies that we used allowed us, to some degree, to touch all of those levels. But was it explicitly designed in? No, I would say. It's only a result of the DDS culture as it was, and as we've evolved it." "I don't think I've seen that, but I can tell you that in my brain, I can imagine one when I see a family, I link it to a CBO, then I link it to SAE, and that's what we're doing. That's my logic model. It's like, if we do all of that, the family will be impacted and will reduce disparities for that specific family. I don't think as an organization, we have a visual tool or a logic model."
Not sure	1	"I don't know that. Research might have a better answer for you on that. I don't want to speculate. I assumed the department looked very...again, I don't want to be flippant to what the department is doing pretty flatly, but just looked across and they looked at numbers, ethnicity, attached it, and that's where we are.

Table 10. Participants' responses of the extent to which DDS differentiates disparities reduction using the following categories

Coding Structure	Frequency	Illustrative Quotes
Availability		
To a great extent	2	"I feel that they focus heavily, and maybe that's pressure from the fact that that's how they're judged most of the time outside of the agency, they focus on utilization and availability"
Somewhat	3	"We are just beginning to recognize that the availability of services for example, with personal directed services or self-determination, offer...if you have more available menu options, it offers an opportunity for families to choose something that's more accustomed to their culture, their experience in life, or what they need."
Little to none	1	"I don't see that."
Accessibility		
To a great extent	3	"Overall, as a department, the accessibility, in terms of reducing disparities of accessibility, there's a very important emphasis on plain language in our documents that we send out. Making sure that they are, of course, accessible from a standpoint of people being able to use a screen reader, or something like that. Using visuals that are appropriate and easy to understand for the public. Making sure that at public meetings, interpreters are available for different languages, and also for ASL."
Somewhat	1	"That's a big area of growth. To me, accessibility is about how we communicate. Whether we're using plain language, physical accessibility of spaces, availability of linguistic options in public meetings. All of that. We've really mastered a few of those. We're still pretty unique in state service event and having multiple interpretation services at our meetings simultaneously. Some of the physical accessibility, I don't think we always look through that lens."
No/not sure	1	"I don't see that either. Maybe, because I don't work in this area.....I also think every regional center works differently. That's where I think some of the trouble we get into."

Table 10 (continued). Participants' responses of the extent to which DDS differentiates disparities reduction using the following categories

Coding Structure	Frequency	Illustrative Quotes
Acceptability		
To a great extent	1	"Our department has conducted surveys to find out consumer experiences. For example, one of our recent ones was during the pandemic. I could send you a… We might have it published online, but we looked at acceptability of the services people were receiving during the pandemic, for example. Looking at satisfaction in the SAE program as well. Whether the services, they felt, met their needs, and things like that."
Somewhat	2	"I would say that broadly, there is a vision. Recognizing that different types of services are going to be preferred based on a number of different characteristics. Do we have a checkbox to measure that? No. Do we have the array of services where every single person that we serve is going to feel like this is an acceptable service? No. There's many stories that we hear that say, "Well, the only thing I can get is a day program where I do crafts and go walk the mall, and I don't want to do that." We do have now, for example, tailored day services. Now we have another option. If you don't want to do a group setting, you can do tailored day…. There's a lot more attempts by regional centers and provider to provide services in culturally and linguistically competent ways, including having people that look and talk like the people that they serve. We're in the beginning steps of that."
Little to none	2	"I don't know that that's a paradigm that we're thinking about, or a lens. If I'm being honest, I don't know that that's part of the conversation. I certainly think it's something that we like to think about in my own team. Is that something that's part of the narrative at the department? Probably not."
Not sure	1	"I don't know what's going on with acceptability. Maybe it's just me not understanding what DDS is doing in terms of that or what that encompasses itself."

Table 10 (continued). Participants' responses of the extent to which DDS differentiates disparities reduction using the following categories

Coding Structure	Frequency	Illustrative Quotes
Quality		
To a great extent	3	"We have a whole quality assurance unit at DDS. I know that we conduct the National Core Indicators survey to assess consumer experiences and family experiences for quality of service and quality of life created by those services. I don't know everything that they do in that section." "Quality, we have a lot of incentives that they're going out with regional center incentives on work. If you do this, you get this. If you do this good behavior, you get this incentive."
Somewhat	2	"I would say somewhat. In my opinion, it's not as much as it needs to be, but there is some."
Little to none	1	"I don't think so."
Utilization		
To a great extent	5	"We definitely have performed a lot of analyses related to utilization by race and language for DDS. For a lot of informative purposes for the leadership, and also for decision-making." "I would say that's our strongest thing because again, it's the easiest thing to measure. We have our purchase of service, we have our consumer characteristics. We can match them up and slice them up. We can say a lot about those."
Somewhat	1	"I think somewhat, but again, if some groups are utilizing more than others, then what is DDS doing for groups who's not utilizing it?"

Table 11. Participants' responses to what measures are employed by DDS to document the extent to which SAE grantees use culturally competent approaches in the following categories

Coding Structure	Frequency	Illustrative Quotes
Translation		
Not sure	6	"I don't think it's documented accurately…I'm already experiencing this with the language access and cultural funds, and this is for regional centers. If they feel like, 'Oh, I haven't done anything,' then they won't document. Also, they don't know what to document. They've never been, again, trained or have the capacity level to document." "I don't know that there is something in place that we have as a grant program to document that, that our grantees are using culturally competent approaches." "The only evidence that we would have with that is they identify the professional organizations that perform the translations. I know that in some of those translation projects, there have been committees and work groups that oversee the translation process to ensure that it's accessible for the communities in which they're intended to serve." "I don't know what we're doing as a department, what kind of measures we're employing. I do understand that they have regional centers comply with equity measures and some other measures, but I am not very familiar with what they're actually measuring or how they're doing that or what it relates to."
Outreach		
Pre and Post surveys	2	"We do. We have measures that determine their surveys pre and post. You have pre and post-surveys that determine…for example if you had training, what did people learn from that training? We do have some of those, so you can measure if there's an increase in knowledge."
Not sure	2	"We don't know that until they put it in their report, but I don't see anywhere where it says in our policy, when you report that you must do this, because for regional centers and CBOs, I'm sorry to say it, [removed for anonymity], you have to put it in very specific order, or they will say, "You know what, you don't have it in our grant agreement, or you don't have it in this"

Table 11 (continued). Participants' responses to what measures are employed by DDS to document the extent to which SAE grantees use culturally competent approaches in the following categories

Coding Structure	Frequency	Illustrative Quotes
Workforce capacity		
Look at hiring practices	1	"Yes, absolutely. You'd look at how many staff have you hired, bilingual, and they offer bilingual incentives, although that will change with new policy initiatives. That is one lens. How many additional folks have you hired, what your focus languages are based on the data of that region?"
No explicit measures	4	"Again, it's the same answer. We have a description. They have a description of how they're conducting their capacity. They also hire consultants, but I don't think there's any explicit measures."
Parent education		
No explicit measures	4	"I don't think there are any measures for that." "It's the same. It's, 'Do we see it in a quarterly report? Are we hearing about it from participants?'"
Promotora		
Measures training by community connectors	1	"We do have a measure that requires the projects to describe all of the training that the community connectors have, which could include cultural competence. Overall, for measures of cultural competence, the idea that I see is that the SAE program has deferred to these projects as the cultural experts. The assumption is that they are conducting culturally-competent practices, because they have the experience working with the target population, and being a part of it."
No explicit measures	3	"We know that promotoras are helping them, and community navigators are helping them. It's not being documented as in saying, "Hey, I'm helping them in regional center services. It was specifically on early start. I'm helping them not only on early start. I help them in generic services, too." That's not captured."

Table 11 (continued). Participants' responses to what measures are employed by DDS to document the extent to which SAE grantees use culturally competent approaches in the following categories

Coding Structure	Frequency	Illustrative Quotes
Family/consumer support services		
No explicit measures and/or lack of documentation	3	"I can't think of any"

Table 12. Participants' responses to what measures are employed by DDS to document the extent to which SAE grantees use linguistically competent approaches in the following categories

Coding Structure	Frequency	Illustrative Quotes
Translation		
No explicit measures	6	"We say we offer the service, but I don't think we have any specific measures. We don't have a standardized, "You got to pass this test with this set of vocabulary, and produce this to become competent." To have some kind of certification that we believe that you are delivering an accurate service." "That is one of the things we strive for. I don't think we're fully there yet. Let me give you an example. We had one of our first grassroots organizations focused on the ASL deaf and hard of hearing community this year."
Outreach		
No explicit measures	4	"Again, we count numbers, or count materials that were handed out. It's too hard to understand that, "Oh, yeah. I called you and approached you because I got a flyer or a table." "I don't think there's any measure."
Workforce capacity		
No explicit measures	4	"I can tell you that some of my grantees are doing culturally competent things and what they're doing linguistically is fine just because I know them and I've interacted with them. I've seen their work and all of that, but we have no measures to track."
Parent education		
No explicit measures	4	"No measure." "Same thing for parent education"
Promotora		
No explicit measures	3	"I don't think there's any measure. Again"
Family/consumer support services		
No explicit measures	4	"No, I don't think there is one. Again, the assumption is that the folks conducting these are the cultural and linguistic experts."

Table 13. Participants' responses to whether the fact that disparities reduction, like cultural competence, is a developmental process that occurs over time and not in 1–2-year increments was considered in the design of the SAE grant program

Coding Structure	Frequency	Illustrative Quotes
To some extent	3	"I would say that the way it was taken into consideration is because it was a permanent funding source. The $11 million is permanently in our budget. It is. Unless somebody reduces it out in a future budget cut, it's there year after year after year. Systematically, that's a through line, similar to CRDP. That's a through-line. The one to two-year duration of a grant project is an administrative limitation of the way that the state of California runs." "We know that one year is not enough. Traditionally, the department had awarded people on one-year grants, sometimes two if they're bigger projects. What we see is the first year, the first eight months of a grant are often getting your feet about you. They are hiring people. When you have to hire your parent navigators, that's the key aspect of your project. It takes you a couple of months… Almost across the board, we see people in their first six months not struggle, it's just to begin, to start a brand-new project. What we see is those that have been awarded in consecutive years, by their third year, are much better. They're better in reporting. They're better in their data and how they collect it, when they collect it. They are more consistent."
Little to no extent	2	"I don't think it was taken into consideration. I know that the program is relatively fairly new, and they were pretty much creating and re-adapting as they went. I do think we would benefit from having longer time frames and periods of time for a CBO to do work to see what's working, to analyze and make adjustments…Luckily, we have returning grantees that are doing the same thing but coming back to us every year, that helps them because they have been doing that for three years. For a brand-new grantee, 12 months is not enough. They may take up to nowadays, four to six months, just to hire someone."
Not sure	1	"I don't know how this was taken into account for the design of the length of the grants."

Table 14. Participants' responses to how feasible it is for DDS to restructure approaches and components of the SAE program based on what is learned from this evaluation

Coding Structure	Frequency	Illustrative Quotes
Highly feasible	4	"I would say really feasible, I hope. I think we have a team that wants to improve what we're doing and a team that just is willing to look at other alternatives of how to do things, and what might be needed. Ultimately, it hopefully become something that we can use to educate regional centers, to educate legislature, and maybe to build out budget proposals." "It's really feasible. Every year, sending out new guidelines and new focus areas, if this evaluation shows that the program can be improved in certain areas, I don't think there'll be any hesitation by DDS leadership to maneuver in that direction."
Feasible	2	"I hope it's feasible. It seems to me that leadership of DDS, they want to do the right thing...I don't think we'll have opposition in terms of feasibility. I don't know how budgets work here at the department or the state of California, but we need staff to run a good program too, I don't know how feasible it is for us to have the right staffing to run an effective program. That's beyond me, but in terms of not just money, but actual support from leadership, I think it's feasible."

Table 15. Participants' responses to what they have found to be the most significant challenges in implementing the SAE grant program

Coding Structure	Frequency	Illustrative Quotes
Staffing concerns	5	"First of all, the lack of staff..... An entire grant program was on our shoulders. That was separate from everything else we do. It was atrocious." "There hasn't been enough time and staff to support in progress evaluation. Most of our efforts, we've only been able to keep up with trying to make sure that the data was good quality, as opposed to having any time to analyze." "We need more representation, we absolutely do, at the leadership level as well. I know the regional centers are trying to hire more service coordinators that match the communities they serve. Again, if management and the higher executives don't necessarily reflect that community, we also see some biases and some other things. We need more representation, absolutely."
Limited RC and CBO collaboration and partnerships	2	"At least from a state perspective, from what I've seen, regional centers have struggled to bring CBOs into the fold as a system partner. There is still at arm's length about working with a CBO in certain regional centers, and not necessarily seeing them as a partner in the same way that a residential care provider might be seen as a partner."
Allocation of funding	1	"The most significant challenge was deciding how to allocate the 11 million, deciding which regional centers and CBOs should actually be awarded."

Table 16. Participants' responses to what they have found to be the most significant challenges in evaluating the SAE grant program

Coding Structure	Frequency	Illustrative Quotes
Limited infrastructure capacity	5	"Evaluating, again, it's the capacity, and then also the lack of investment. If we don't have that capacity within, we need to invest outside to assist us to get that. It can't just be [withheld for anonymity] and some of the programs and stuff. It can't. It's not possible" "From the beginning, the infrastructure support at DDS has been not enough to support the program. There's been more people hired, but there's a lot of grantees. There's 55 every year."
Sole emphasis on POS	2	"I think one significant challenge is that there's a huge emphasis on POS as a metric. Many of these project types are almost impossible to show a direct connection to POS change." "I find it challenging to work on a program that gets heavily judged on POS change. When I think about the program, I don't think it was originally designed to change POS directly. If you look at our project types, one was about translation, one was about outreach to the community or education. Those are great things to do for a community. However, you can't trace that. You don't necessarily find the direct correlation to a POS change. It seems to me that we're being judged on changing POS, however, the program once assigned to empower individuals in other areas that it makes it hard to make that link. When it comes to evaluation, I can tell you that we're doing great work in terms of families that we have impacted, but it doesn't always seem like that when you look at the POS overall."

Table 17. Participants' responses to what other efforts the department is undertaking, in addition to the SAE grant program to: (a) increasing equity, (b) decrease disparities

DDS submitted a detailed listing and description of the additional efforts the Department is undertaking to increase equity and decrease disparities. This document is included in Appendix E.

Table 18. Participants' responses to the disparities that are outside of the department's control that impact persons with IDD and their families from racially, ethnically, culturally, and linguistically diverse groups

Coding Structure	Frequency	Illustrative Quotes
Financial challenges	2	"I would say first and foremost, poverty in general. Lower income, lack of resources to get access to all resources, so generic resources across the board. I always feel like it depends on whatever is most pressing for a family as to how they access service." "Well, everything else outside of DDS impacts the families. It's hard to support a family or to ask them to show up to a therapy or an event or something or an IPP meeting, if they're currently being evicted or if they don't have food and they're worried about their next meal."
Unstable housing	2	"That would be respite, in-home support services, ABA autism services, speech and language therapy. Things that would happen in a home. If people are experiencing unstable housing, it's very difficult to set those services up. Access to healthcare in general. I know we're under that umbrella, but we're one wing of it." "If they don't have steady housing, then you're not going to have behavioral therapy come to your house."
Healthcare needs	2	"The actual bigger wing of health and human services, and access to affordable healthcare impacts how people utilize our services. We're an entitlement, and while people should be getting all the services that they need, if there are other health issues that are more primary for a mother, or a father, or another child in the family, or whichever, our services may not be prioritized, and so they might be looked as less important. It's just that they're not the priority of the moment." "Also, the department doesn't have to do it all. The department should be collaborating and partnering with the sister agencies under Health and Human Services, and that should be reflected to regional centers, too."

Table 18 (continued). A more detailed breakdown of participants' responses to the disparities that are outside of the department's control that impact persons with IDD and their families from racially, ethnically, culturally, and linguistically diverse gro ups

Coding Structure	Frequency	Illustrative Quotes
Regional Center autonomy	2	"I feel like, again, the state funds all 21 regional centers, right? The state should be driving how those regional centers, I would think, how they operate, and consistently operate throughout the state. It's not like that. It's not consistent. It's not standardized with that." "Local, regional center politics are, in some ways, out of department's control, although it could be less out of the department's control. By our choice, they are independent non-profits and so we give them a lot of autonomy."
Impact of internal and external regulations and laws	2	"I think about the institutional ways that we think about the rules that we've created, even things like parental responsibility. Something we like to say at the regional center level, when a child is under 18, we say...Let's say your child doesn't have 100 percent top dental hygiene routine down. One solution would be, let's do more frequent dental cleanings. We know that dental cleanings are twice a year through your dental insurance, at least in California. What stands in the way of the regional center funding additional cleanings to preserve people's teeth? It's this thing called parental responsibility, which basically sets up an inequity right from the start. If I'm a child in a family with resources and time, my teeth can get cleaned out of my parents' pocket, and I might have better teeth at 18 than if I don't." "Some rules that are established outside of the state system. Immigration laws play into it. The social environment, the things that are going on in the world impact it. There's funding and there's legislative things that are passed outside the states."
Personal and/or cultural preferences	1	"Things that are outside of our control is people's preferences and values of what services they do and do not want, that may affect whether they have...For example, family members who are older adults with disabilities may still be living in the home for some cultures. In other cultures, they may be out of the home, which is much more expensive for POS."

Appendix E

DDS Written Summary in Response to Interview Question 17

DDS SERVICE ACCESS & EQUITY SUMMARY OF PROJECTS & PROGRAMS 2023

Our Vision
People with intellectual and developmental disabilities experience respect for their choices, culture and language preferences, their beliefs, values, needs, and goals, from a person-centered service system made up of a network of community agencies that provide high quality, outcome-based and equitable services.

Background: In 2017, DDS developed a vision statement with federal partners through our Community of Practice with Georgetown University National Center for Cultural Competence. In 2022, DSTF Members helped to update this statement. This vision has helped to guide our work to develop strategies to become a more accessible and equitable system for diverse communities.

Equity is the lens by which we see our system & guides all of our work at DDS

➢ **Supporting California's ethnically diverse population <u>requires a multifaceted approach</u> that includes listening to communities for creative and flexible solutions that address needs, staying focused on goals of improving equity, service access and cultural competency.**

➢ Lifting up community voices from diverse communities though meaningful engagement has helped DDS develop policy more responsive to needs of families.

➢ **Breaking barriers has launched focus groups to spend time discussing challenges to service access and how people from different cultures access services differently. These nuances are not fully explained by data but require meaningful conversations to understand.**

➢ As the most populous state in the country, California also has one of THE MOST ETHNICALLY DIVERSE populations in the world.
- ▪ **21 REGIONAL CENTERS cover ALL 58 Counties in CA – serving approximately 400,000 people with developmental disabilities.**
- ▪ More than half of ALL consumers are from communities of color – 40% are HISPANIC (=140,000). Note: Of the *40% of all Hispanics served, 67%* are UNDER THE AGE OF 22 years (=98,000).
- ▪ **FY21/22 autism counts are for all active consumers (with or without POS). SOURCE - Comprehensive Dataset CMF on 1.30.22**

Meaningful Community Engagement

Key to building trust in the community is to connect, listen, learn and follow through with plans, commitments, and agreements.

- **Developmental Services Task Force (DSTF) Service Access and Equity Workgroup** – public meeting as needed which is comprised of individuals from diverse communities, service provider groups, advocates, and regional centers.

- **DDS African American Focus Group** – monthly meaningful opportunity to have more intimate conversations and robust discussions on the needs of the African American community. Group includes leaders within the African American community from family members of individuals served, service providers, grantees of the SAE Grant and regional centers.

- **DDS Community-Based Organization Meeting** - 75+ community leaders learn, share, & collaborate in this 2-hour meeting. DDS shares resources from CBOs, RCs, state, local and government agencies. This connection is a safe space for sharing, learning and identifying barriers within regions, communities or populations. The meeting has been identified as rejuvenating and empowering for participants.

- **California Tribal Families Coalition** – Monthly meeting and collaboration with Native American leaders from CTFC sharing their contract work with 3 lead RCs and also share collaborations and events for inclusion of RC community. Purpose: monitor ongoing contracts, discuss RC staff training needs, address barriers, and share resources.

- **Family Resource Centers Network of CA (Navigator Program)** – monthly meeting to connect with leadership from the statewide network of Family Resource Centers to identify monitor ongoing contracts, consider navigator training needs, address challenges and share resources.

- **Host Multiple Individual Parent/Family Meetings in Spanish** (Latina Moms)

- **DDS Latinx Focus Group** – organization is underway for Spring 2023

Equity Programs and Initiatives

The Department is committed to using the lens of cultural and linguistic competence to focus on disrupting social injustices and racial inequalities within the developmental services system. As California builds upon its investments in equity, the Department reinforces its efforts to advance service access and equity to support individuals with developmental disabilities from marginalized communities. Successful Service Access and Equity Grants focus on measurable progress in reducing disparities, advancing equity and shifting the developmental services system to attain improved outcomes for diverse communities.

Service Access & Equity Grant Program ($11M Annually) – important "seeds" of new ideas that have become new statewide initiatives, fostered strong community partnerships, diverse resources created. Grants are one strategy/tool to improve equity. 400 grants awarded since 2016 and over 200,000 people served/supported/reached. Invaluable to learn, understand, and listen to community leaders and families about their needs, choices and ideas to improve the system.

- **Assembly Bill X2 1 (2016) established the Service Access and Equity GrantProgram (Formerly "Disparity Grant Program") Grant Program**
- For FY 22-23 - Additional $11M for one-time expansion of grant

Grant Focus for 2022-23 - to reinforce effective strategies that will lead to a culturally and linguistically responsive developmental disability service system to improve service access and empower all individuals and families served.
- Expanding inclusive employment opportunities for individuals with I/DD
- Increasing a culturally & linguistically responsive service provider workforce
- Creating community partnerships for learning and advocacy
- Improving access to Early Start services for diverse communities
- Cultivating meaningful tribal engagement with the Native American community
- Increasing access to deaf services and resources for self-advocates and families
- Developing culturally and linguistically competent resources and educational opportunities for self-advocates, aging caregivers & new parents
- Advancing person-centered services and supports for foster & transition-age youth, and individuals from the LGBTQ+ community

Examples – SAE Grant Projects
- Access Nonprofit Center Training / Support for black families with babies at risk
- Amigo Baby Inc - Phone Application to improve access to Early Start services/resources
- Stanford University - Bilingual /Bicultural Family Empowerment Coaches provide 1:1 training for family members
- Chasing 7 Dreams - Parent education to promote early diagnosis for babies
- Children's Hospital of L.A. Establish sustainable public health consortium of disability agencies and CBOs
- Early Years Therapy to increase tribal community awareness of and trust in ES
- Friends of Children with Special Needs – community connector program for Chinese and Vietnamese Families
- Frank D. Lanterman RC Navigation and 1:1 peer support for Self-Advocates
- Korean American Special Ed Center – creating culturally competent Early Start resources in native language - Korean – understanding/awareness in new ways
- Hmong (Hmong Youth Parents United) – assisting monolingual elders in accessing technology to support their loved ones in multigenerational homes
- Tribal Engagement (Acorns to Oak Trees and CTFC) – raising awareness and understanding of I/DD within tribal communities in with cultural tory telling
- DVU – Emerging Leaders Program, mentorship, empowering self-advocates
- Autism Society of LA - training multilingual SDP Independent Facilitators
- Vietnamese (Boat People) -Empower Vietnamese; bridging Mental Health Gap
- CHLA –Navigator project located within Pediatric Clinic @ hospital
- Chinese (Diversity in Training Institute) - creating a pipeline to increase linguistically competent service providers in respite – to improve the experience

- Parent Black Children – empowering cohort of black parents to learn more and develop leadership and advocacy skills
- Special Needs Network – Increase awareness, advocacy, service engagement with families for children under 5/at risk; FY21/22 Navigator Program launched
- ICC – Integredoras direct support/ Hispanic families to access multiple systems
- Mixteco – Indigenous parent navigation in their native dialect (Mixteco)
- C.LA.S.E. – (Coachella Valley) - developing Latinx leaders/building CoP
- Family Resource Navigators - "Tea" Sessions with Arabic, Dari & Farsi speaking
- East Asian (PRAGNYA) – empowering self-advocates and families through Napalese, Pakistani, Shrilankan, Bangladeshi and Afghan outreach/engagement
- Contra Costa Health Services – Focus on unmet needs of mental health services for I/DD with leadership from Self-Advocates - Started slowly due to hiring delays for Self-Advocates but good project focus
- Special Needs Network – Behavior Tech Apprenticeship Program expanding ABA Providers in minority communities with focus on African American and Latino to serve as therapists and consultants – Great idea; will need shaping and technical assistance

Independent Evaluation of Grant Program - ($0.5M one-time with extension) - One-time funding for an independent evaluation of the Service Access and Equity Grant Program. Contract with Georgetown National Center on Cultural and Linguistic Competence. Goal: Provide recommendations to prioritize areas of focus, populations, and interventions to have an impact of disparities reduction at all levels. Root cause analysis to be part of report to consider whether disparities (products of inequities) are found at the individual, family, community, organizational and systems levels.

- Fall 2022 - Conducted quantitative and qualitative data analysis using grant program reports and DDS administrative data per regional center across demographic groups, portals of entry into the DDS system, and other factors to assess increased access and/or disparities reduction across multiple grant years.

- March 2023 - To complete structured interviews with directors of RCs and DDS; convened listening sessions with CBOs, cultural specialists, and families; and conducted surveys for CBOs. Analysis to be completed to assess the extent to which the SAE grant program impacted disparities reduction and/or promoted equity by increasing access to information, supports, and services.

- April 2023 - Interim report to be submitted with preliminary findings to restructure the SAE grant program with recommendations to focus on types of projects most likely to lead to disparities reduction and increased access over time (thereby promoting equity) that have impact on the individual, family, community, organization, and system levels.

Community Navigator Program ($5.3M Annually) – Build on the community health worker model with statewide community navigators with lived experience, shared culture, ethnicity & language supporting individuals/families to utilize and access services, to build trust with RCs. With a statewide contract with long-time trusted partners of the Family Resources Centers, this initiative is one pf the seedlings from SAE Grant projects with integradoras, promotoras and navigators. Navigators are in each of the 21 catchment areas to utilize and access services and to help build trust w/ RCs.****DATA indicate service access increased 72% for participants in a DFP Promotora project, compared to 13% who did not participate in a DFP Promotora project*

Highlights of Community Navigator Program
- o 1,200+ people served (9 months)
- o 2,693=Services provided (support groups, navigation for RC and generic resources, parents/self-advocate getting trainings)
- o 45 Navigators hired to date
- o 6 statewide trainings for navigators to build capacity include: DDS Data Tracking, SDP, SPED, Lanterman, IHSS/DRC and Navigator Leadership Training

Early Start/Tribal Engagement ($0.5M Annually) – to increase trust with tribal communities, support awareness/education, develop culturally competent trainings, and Tribal Engagement Guide. This collaboration with the California Tribal Families Coalition and 3 Lead RCs (San Diego, Kern and Far Northern RCs) help to support the 1st American Indian Disability Conference at Sycuan Band of Mission Indians. This inaugural event included multiple California tribes, RCs and families engaged in listening sessions, trainings, and awareness meetings. Valuable efforts to connect RCs with their local tribal communities to foster respectful and meaningful new partnerships.

Highlights of Tribal initiative
- o Over 36 of 109 federally recognized tribes were engaged and participated in outreach events, family surveys, learning opportunities, listening sessions in the first of the year.
- o Multiple Listening Sessions hosted statewide for Tribal Leaders & Families
- o Tribal Engagement Guide developed in collaboration with RCs and DDS
- o Tribal Engagement and Cultural Competency Training ongoing with RCs
- o Culturally Competent RC Outreach materials developed for families
- o 2nd Annual California American Indian Disability Symposium - Fall 2023
- o CTFC to include I/DD Services Workshop in the Indian Child Welfare Act (ICWA) Conference

Language Access & Cultural Competency Program - ($16.7M Annually) – Developed statewide program where all 21 RCs developed comprehensive language and cultural competency plans to reflect their data of language, ethnicity & culture to better support the language and culture needs of individuals with developmental disabilities, their caregivers, and their family members.

- *Funding to Improve Language Access and Cultural Competency – DDS Directive issued on April 6, 2022 -* Funding to Improve Language Access and Cultural Competency
  - o Identify vital documents & website content for translation
  - o Host specialized orientations, group/family information sessions
  - o Conduct regular & periodic community language needs assessments
  - o Coordinate & streamline - interpretation & translation services
  - o Implement internal & external quality control measures

- RC plans include hosting Listening Sessions to expand community input to develop responsive plans that will improve the experience & access to information for multi-lingual, monolingual, and diverse cultural groups. The goal is to outline innovative ways to engage with, learn from and partner with diverse communities

- See, Welfare and Institutions Code 4620.4

22/23 Focus of RC Plans – By Language

ASL – 18	Mandarin – 6
Arabic – 5	Mayan/Mam – 1
Aramaic/Chaldean – 1	Mixteco – 1
Armenian – 2	Punjabi – 1
Cambodian – 2	Russian – 2
Cantonese – 7	Spanish – 21
Farsi – 2	Tagalog – 11
Hmong – 3	Vietnamese – 11
Korean – 3	

22/23 Focus of RC Plans – By Population & Culture

African American	18
Native American	11
Asian	18
Middle Eastern	1
Latinx/Hispanic	21
Pacific Islander	7
LGBTQ+	10
Unhoused	1

Building Capacity - RCs recruiting staff with language and/or cultural expertise to build bridges to better support the needs of diverse individuals and families served and reach communities of color

- Multiple RCs hiring staff with language specific skills:
  - Chinese, Korean, Japanese and Spanish
  - Bilingual stipends offered for staff retention
- CVRC and VMRC hired a Diversity, Equity and Inclusion Manager
- NLACRC hired LGBTQ+ Specialist

LACC Partnerships & Collaborations
- CVRC & VMRC to host Southeast Asian Conference (Fall 2023)
- FDLRC will partner with 6 CBOs with diverse language capacity to help prioritize & guide efforts to implement LACC
- GGRC & RCEB partnering to focus on Bay Area families within the
  - Native American community; and
  - Deaf and Hard of Hearing community
- IRC hosting SAE Conference (April 1, 2023)

Unique Focus Areas of LACC Program
- HRC launching text message campaign in Khmer, Korean, Spanish and Tagalog
- NBRC contracting with a videographer to create Spanish videos in Tele-Novela
- SCLARC further developing the Bilingual Family Portal to connect with and share African American and Latinx individuals directly
- RCEB and TCRC to focus on indigenous languages of Mixteco and Mayan/Mam
- SDRC will focus on unhoused populations of individuals with I/DD by partnering with faith-based and food bank organizations in San Diego County
- FNRC coordinating specialists to work together internally (*e.g.* Cultural Specialist, Deaf Specialist, Employment Specialist and Client Advocates)

Implicit Bias Training ($7M on-going) – intended to raise awareness of unconscious biases to improve and develop the workforce to increase access to services; statewide RC staff to be trained. RC eligibility is the first step into our service system. Implicit bias training is one-way clinicians and RC intake staff can learn new strategies to recognize their own biases (prejudgments) and actively change to be fair in clinical assessments.

- Implicit bias training (or unconscious bias training) is valuable because it:
  1) Raises awareness of our own biases (from our own experiences in life) that we may not even be aware of;
  2) Provides strategies and tools we can use to disrupt these biases; and
  3) Helps to eliminate biases that cause us to make decisions that favor or exclude others. RFP process is underway with upcoming Proposer's Conference.
- Stakeholder Input for Implicit Bias Initiative
  - Clear common vision, flexibility, ability to evolve, practical curriculum
  - Diversity of trainers, safe space, inclusion of self-advocates and families
  - Link outcomes to individuals served with short/long term goals

- RFP process was completed in February and a statewide contract was awarded to EquitiFy. Contract work to begin in the coming days

Provisional Eligibility ($23.8 on-going) - Provide children ages three and four with provisional Lanterman Act service eligibility to start support of families early. Important to capture families at critical developmental ages, and first time eligibility criteria changed since the inception of the Lanterman Act. Studies have shown that African American and Latinx families have a higher percentage of delayed diagnoses of autism. The provisional eligibility increases access to the service system for these and other underserved families with at-risk children. (Implicit bias)

- Early intervention is an evidence-based strategy that has been proven to help young children and their families build skills that will increase the likelihood of their success in school and the community
- Extension of Lanterman eligibility to 3-and 4-year-old provides benefits to children who meet criteria for early intervention but might not meet criteria for Lanterman utilizing standard measures and intake protocols
- Children can be re-assessed at age 5 to determine if they meet Lanterman eligibility utilizing standard protocols (I.Q. testing, adaptive behavior measures, psychosocial and medical background information)

Enhanced Service Coordination (Reduced Caseloads) ($12.8) – Expands effective family support model statewide with 1:40 enhanced caseload ratios where ESC's will serve up to 4,200 individuals. Offers the opportunity for ESCs with expertise to focus attention on individual/needs. RCs have hired service coordinators with experienced staff moving to ESC caseloads. Consumer/Family questionnaire to measure the impact and outcomes of ESC under development to be launched April 2023.

Enhanced Service Coordination at ELARC funded by SAE Grant program (2017)
1. to increase Purchase of Service (POS) expenditures; and
2. to reduce disparity for the Participants.
3. to increase confidence and competency in understanding and navigating the RC system.

Outcomes
- POS has increased every FY during implementation
- Data for all three years is currently available
- POS Data shows a positive correlation between reduced caseloads, enhanced case management services and increases in POS.

Objectives
- Strengthen trust, improve communication, and the service experience for the individuals served and their families
- Understand the needs of the whole family
- Provide education about the RC system
- Better understanding of barriers to accessing RC services

Measures
- Pre/Post Survey - to measure the effectiveness of educational component
- Questionnaire - to understand barriers and
- Satisfaction Survey to measure the consumer/family's experience
- POS Data serves to measure increases in POS for participants
  - Results of Pre/Post Surveys, Questionnaire and Satisfaction Surveys are available for FY 17/18 and FY 18/19. Results for FY 19/20 will be available in March of 2021.
  - All performance measures show positive gains in all three objective areas.

Deaf Resources ($14M (one-time) + $2.3M) – DDS Deaf Access Specialist to provide statewide leadership and subject matter expertise on the provision of services and supports for individuals who are deaf and have intellectual or developmental disabilities. Developing trusted relationships within the deaf community requires specialized experience.

- o Funding for RC Deaf Specialists will support the expansion of deaf service resources, provide training and expertise to regional center staff, and coordinate with DDS on statewide efforts
- o 21 RC Deaf Access Specialists hired statewide to increase understanding, awareness, and resources
- o Deaf Steering Committee being established
    - Stakeholders and subject matter experts will develop recommendations on quality and diversity of services and supports to individuals who are deaf, and communication assessments
    - First meeting to be schedule in March 2023
- o Facilitating the identification of communication assessment tools for RC consumers who are deaf and currently exploring requirements needed for assessors
- o DDS webpage update will include deaf resources related to efforts to improve deaf access and supports

Bilingual Pay for Direct Service Professionals ($6.5M)
- *Support SPs to build capacity to expand language access across the state – any staff person who meets a competency requirement, -- building capacity gives more people choice.*
- Valuing language skills in workforce to expand access to individuals who speak multiple languages
- Diversify service provider workforce & Expand choice of service providers

Coordinated Family Support Services ($41.6M one-time) – listening to community led to development of initiative focused on multigenerational homes -- to provide additional services beyond respite that can be accessed at home; focus on service equity for adults residing with their families

Social, Recreation & Camp ($36.8M in FY22-23)– restore access to regional center services including: camping services, social recreation activities, educational services, and nonmedical therapies which were services prioritized by many of our diverse communities

Develop Culturally and Linguistically Sensitive Services ($4.5M) - Provide training opportunities for Early Start providers in areas that enhance participant outcomes such as addressing implicit bias, adverse childhood experiences and toxic stress, and practicing reflective supervision training. Establish a scholarship and education stipend program to increase the availability of a provider network that reflects the cultural and linguistic diversity of the community.

Outreach and Education to Underserved Populations ($4.2M) - Establish a grant program for targeted and culturally sensitive outreach. Pilot a partnership program between counties and regional centers to train professionals and increase awareness of the Early Start program. Increase capacity and diversify community participation to the Interagency Coordinating Council to support outreach activities and effectiveness.

Family Wellness

- Families who have a child who is at risk for or has a recent diagnosis of developmental disability often face immediate, potentially lifelong toxic stress that impacts the mental and behavioral health of family & threatens the stability of the family unit. Support examples:
  - Learning and/or managing their child's developmental or medical risk, stress over the sudden need to navigate complex systems of care, concerns about financial responsibilities, or related to the pandemic.
  - Early identification of stressors, opportunities to build networks for peer support, help developing effective and positive caregiving strategies, and warm hand-offs to applicable resources.
  - Team of professionals (e.g. LCSW, Nurse, Parent-Peers) who can talk to families when they are facing initial fear of entering a RC system—particularly a delay when accessing behavioral health supports (marriage counseling, family unit support).
    - Positive Outcomes - potential to prevent negative health/wellness outcomes in families, adverse childhood experiences (ACEs), and family crises.
    - Will be culturally and linguistically sensitive and at no cost to families.
    - DDS has identified one RC (potentially 3?) and we are considering other RCs for participation in this pilot

Appendix F

Listening Session Summary: Cultural Specialists

CULTURAL SPECIALIST LISTENING SESSION QUESTION 1

Georgetown University

Q1 How does your Regional Center define equity for the population of people with IDD and their families?

Choice Equity is not about giving everyone the same thing. Equity is about meeting people where they are, understanding what is important to and for them
November 14, 2022

4.2 ☐☐☐☐☐ (8 ☐)Ranked #1
of 10

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We define equity as services being accessible to all with the supports that they need to overcome the barriers to those appropriate services. Eventually, we would like to reach Justice, where barriers are removed and all have true access to services
November 14, 2022

4.2 ☐☐☐☐☐ (8 ☐)Ranked #2
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Increase utilization of funding, teaching advocacy clients and families, providing information about generic resources and cultural, linguistic ser Cultural, linguistic, advocacy, utilization of funding, knowing the system.
November 14, 2022

4.0 ☐☐☐☐☐ (9 ☐)Ranked #3
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Providing services based on the needs of each individual. That people with IDD and their families be able to access services.
November 14, 2022

3.9 ☐☐☐☐☐ (9 ☐)Ranked #4
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Autonomy and sovereignty Giving people the power and tools to lead happy and full-filling lives on their own terms, with the supports they want.

3.9 ☐☐☐☐☐ (8 ☐)Ranked #5
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Equity is to provide the services and supports that each person served would need for them to reach their full potential. It is important because not every one will need the same services, some might need more in order to achieve their goals and quality of life.
November 14, 2022

3.9 ☐ ☐ ☐ ☐ ☐ (8 ☐)

Ranked #6 of 10

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Being able to provide services to the individuals we serve and increasing their awareness of the services we provide so they can utilize them Many individuals and families don't always know everything that our regional center can support them with
November 14, 2022

3.8 ☐ ☐ ☐ ☐ ☐ (5 ☐)

Ranked #7 of 10

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RC promotes person centered planning at the center of its case management processes. We are a large agency with over 800 staff making equity challenging to achieve and to make actual impact at the macro level of the community we serve.
November 14, 2022

3.7 ☐ ☐ ☐ ☐ ☐ (8 ☐)

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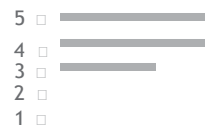
Providing access to services and resources to all stakeholders considering individuality. Because if we do not consider differences as well as similarities, planning and execution will fail.
November 14, 2022

3.6 ☐ ☐ ☐ ☐ ☐ (5 ☐)

Ranked #9 of 10

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They focus on inclusion Because it doesn't exclude anyone
November 14, 2022

3.4 ☐ ☐ ☐ ☐ ☐ (9 ☐)

Ranked #10 of 10

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Georgetown University

Q2 How would you describe the root causes or factors that contribute to disparities in California's system for personswith IDD and their family members from racially, ethnically, culturally, and linguistically diverse backgrounds?

Lack of education in families and, most times, not speaking or understanding the language. Miss information is given to many families.
November 14, 2022

4.1 ☐☐☐☐☐ (9 ☐)
Ranked #1 of 14

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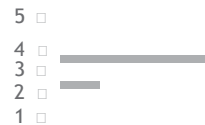
Cultural beliefs, language barriers, not understanding the system, socioeconomic status, and fear of using government funds. To increase the number of participants, to provide services, and to be able to do the work that we are meant to do.
November 14, 2022

4.1 ☐☐☐☐☐ (7 ☐)
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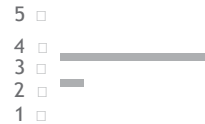
Some of the root causes for disparity would be the lack of knowledge on the regional center as well as the lack of accessibility to resources not all of our communities have access to all of the resources they need and that are available to them
November 14, 2022

4.1 ☐☐☐☐☐ (7 ☐)
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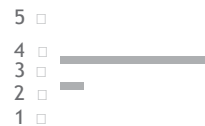
Stigma For years, individuals with DD's have been historically oppressed, hidden away, disregarded and not included as valuable members in their communities.
November 14, 2022

4.0 ☐☐☐☐☐ (9 ☐)
Ranked #4 of 14

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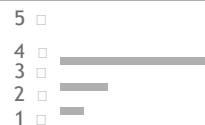
A big root cause which contribute to disparities is that these systems were not designed to be inclusive for all, making them hard to navigate. Its important that everyone is included at the table - break the cookie-cutter mold of how services should be provided and who can access,
November 14, 2022

3.9 ☐☐☐☐☐ (8 ☐)

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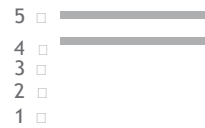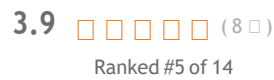
Location Regional centers that serve a high number of clients will have more difficulty serving everyone equally. Rural communities dont have the same access
November 14, 2022

3.9 ☐☐☐☐☐ (8 ☐)

Ranked #6 of 14

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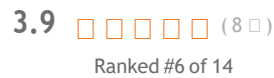
Cultural differences Both families might need the same services, but this needed service might work for one but not the other family due to cultural background.
November 14, 2022

3.8 ☐☐☐☐☐ (8 ☐)

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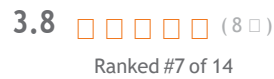
Lack of cultural proficiency The processes need to be simplified
November 14, 2022

3.8 ☐☐☐☐☐ (8 ☐)

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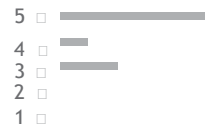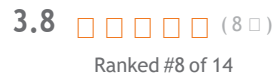
Lack of knowledge and information Fear of public charges, and not knowing what services are available
November 14, 2022

3.8 ☐☐☐☐☐ (7 ☐)

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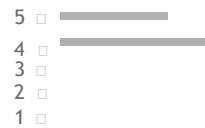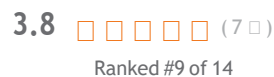
My thought is that one of the root causes is that the system was never built for people with IDD and there has always been a battle to level the field It is important because we need people to participate in political activity to guarantee equal opportunities and funding.
November 14, 2022

3.7 ☐☐☐☐☐ (8 ☐)

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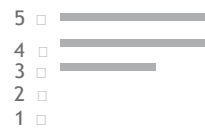
Awareness Having trainings to have more awareness of the disparities in our systems. Helping our CSC understand how to help our families by being culturally se
November 14, 2022

3.7 ☐☐☐☐☐ (7 ☐)

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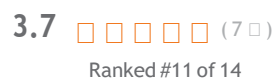
Values Our country places more value in things like policing, war, the military as opposed to social services which determines where money goes
November 14, 2022

3.5 ☐☐☐☐☐ (7 ☐)
Ranked #12 of 14

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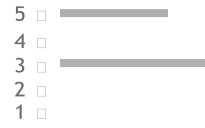
Services and purchase of services guideline are different across RCs It is hard for families to learn and navigate, especially families move to different RCs.
November 14, 2022

3.4 ☐☐☐☐☐ (2 ☐)
Ranked #13 of 14

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Lack of education Some families from different cultural backgrounds do not even understand or know what DD's are.
November 14, 2022

3.2 ☐☐☐☐☐ (1 ☐)
Ranked #14 of 14

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Georgetown University

Q3 What do you view as the role of the Cultural Specialist in disparities reduction in the California IDD system?

The role is to connect with families and individuals served and identify ways of how we can better support them to access services & resources We are able to build a relationship with the communities we serve, speak their language and help them remove the barriers they face
November 14, 2022

4.2 ☐☐☐☐☐ (9 ☐)
Ranked #1 of 13

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Being a voice Speaking up for our underserved communities and holding people accountable (internally and externally)
November 14, 2022

4.1 ☐☐☐☐☐ (9 ☐)
Ranked #2 of 13

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The CS is the voice that continues to speak about disparities even when that topic isn't on the top list of priorities of a regional center. The CS is the one that focuses on addressing disparities with SAE grant projects, through targeted outreach, and meaningful collaborations.
November 14, 2022

4.1 ☐☐☐☐☐ (9 ☐)
Ranked #3 of 13

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To be the bridge between the community and the Regional Center. Support families and Regional Center staff when asking or SC providing services. To be able to identify disparities among our families in the Regional Center.
November 14, 2022

4.1 ☐☐☐☐☐ (9 ☐)
Ranked #4 of 13

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Ambassador between RC, person served and their families Breaching the gap of information, provide extra support and conflict resolution when needed.
November 14, 2022

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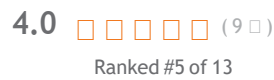
Valued Community Member Being someone that the community trusts, welcomes, being the one who is reaching out & offering a hand. Being someone who listens & responds to needs
November 14, 2022

4.0 ▢▢▢▢▢ (9 ▢)
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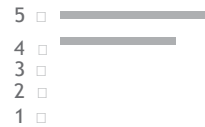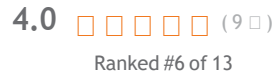
Attend the collaborative meetings, and sit on various advisory committee. To build the connection between different agencies and programs, as well as to outreach to underserved communities.
November 14, 2022

3.9 ▢▢▢▢▢ (9 ▢)
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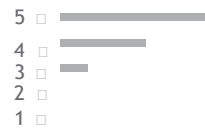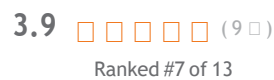
Awareness to the families and consumers and regional center, having discussions on what is missing and how to meet the need. Bringing everyone to the table to make the changes necessary.
November 14, 2022

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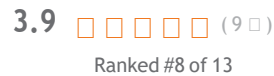
Cultural Specialist support the agency in its efforts to become more culturally competent and addressing the disparities seen in our service access Our communities and individuals need RC services - RCs are not yet equitable in their information & services, so they cannot use the services
November 14, 2022

3.9 ▢▢▢▢▢ (9 ▢)
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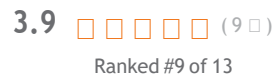
Liaison Being a point of contact for staff who may need resources or connections to other community organizations
November 14, 2022

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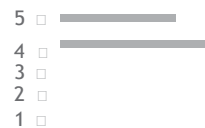
A local individual who listens is aware of the needs of the people we serve and makes sure to help fill the gap. Advocates with DDS via grant funding It helps the community know about our services, create projects that benefit the people we serve, and work closely with the CBOs.
November 14, 2022

3.9 (8)
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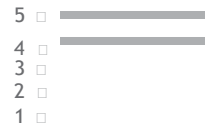
Cohesiveness Making sure everyone understand equity, inclusion, the importance of cultural awareness and streamlining resources/services for underserved families
November 14, 2022

3.8 (8)
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Help identify disparities through research and direct conversation with families and clients and planning the best way to reduce them For example, we first need to know why we are not successful, whether is due to language barriers, economic disparities or other. Then we can adjust.
November 14, 2022

3.7 (8)
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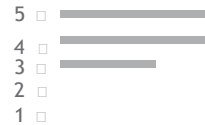
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Georgetown University

Q4 How have you been involved in the Service Access and Equity (SAE) grant program in your Regional Center?

**My role is to come up with projects, do the research, write the grant, manage the project and budget, and report on it. Then do it again the next yr.** Cultural Specialists see the disparities, we have the connections, we know better than anyone what the work we should do is and how it can be done.
November 14, 2022

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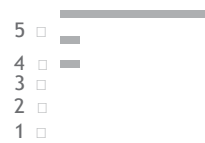
As the CS, I wrote, submitted, managed, and reported on the SAE grants. This was a challenging but very enlightening and rewarding opportunity that helped me view disparities from different perspectives.
November 14, 2022

4.0   (9)   Ranked #2 of 10

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I have been involved in the project development, write and oversee the grant projects. As a CS, we are able to know the needs of the community and what we need to do in order to meet the needs and close the disparity gaps.
November 14, 2022

4.0   (9)   Ranked #3 of 10

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I have been included in developing the grant ideas or giving my input. Writing the grant, monitoring the grant, and reporting quarterly data. Cultural specialist have a connection with the community.
November 14, 2022

4.0   (8)   Ranked #4 of 10

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As CS providing collaboratives within CBOs to bring trainings and awareness to the CSC This allows for the CSC to know what resources are available in their areas and what resources to provide their families.
November 14, 2022

3.9 ☐☐☐☐☐ (9 ☐)
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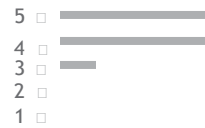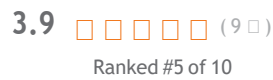
CBO Collaboration Making sure that CBO's have accurate info about RC's & feel supported. Exchanging info about disparities and barriers. Working toward the same goal
November 14, 2022

3.8 ☐☐☐☐☐ (7 ☐)
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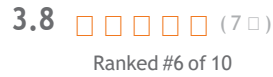
I make sure that our RC proposals are submitted, I read the other org proposals and provide feedback & implement some of the programs I have a good understanding on what our community's needs are and how to better support them
November 14, 2022

3.8 ☐☐☐☐☐ (7 ☐)
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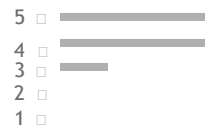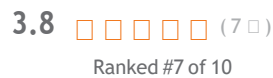
I work closely with the SC'. I have been writing the grants since the inception of the position. I work closely with parents, vendors, and generic res I want to ensure the individuals we serve, and have a voice, and I translate that into grants, community outreach, service delivery, or devel.
November 14, 2022

3.8 ☐☐☐☐☐ (7 ☐)
Ranked #8 of 10

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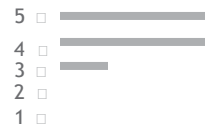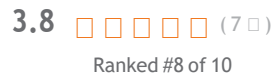
Liaison LiaisonI provide our subcontractor with information about RC, processes, services offered, POS data, and relay information to stakeholders internal
November 14, 2022

3.7 ☐☐☐☐☐ (9 ☐)
Ranked #9 of 10

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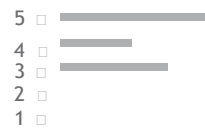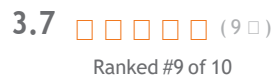
Primarily in a supporting role with software, writing, and helping in event planning. Is important to know how to use the software and writing according to requirements for reporting purposes and plan events with minimal friction.
November 14, 2022
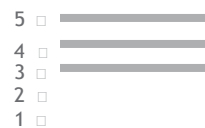
3.5 ☐☐☐☐☐ (6 ☐)
Ranked #10 of 10

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Georgetown University

Q5 What recommendations do you have for DDS about disparities reduction?

Continue to provide funding for interpretation and translation. Providing a more up-to-date POS Expenditure data, if possible, and earlier. To create more focused projects. So that RCs can identify CBOs who can collaborate on these projects and have discussion.
November 14, 2022

4.2 ▢▢▢▢▢ (9 ▢)
Ranked #1 of 11

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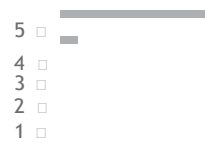
Enhance better collaboration between RCs and CBOs that are funded through SAE grants. Lack of communication, and accountability. Families were provided inaccurate information which could lead to negative relationship between RC & family
November 14, 2022

4.2 ▢▢▢▢▢ (9 ▢)
Ranked #2 of 11

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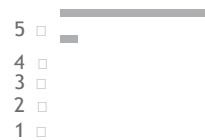
Data Having data from the previous FY before submitting SAE and other DDS grants so that we are accurately addressing the needs of the community.
November 14, 2022

4.1 ▢▢▢▢▢ (9 ▢)
Ranked #3 of 11

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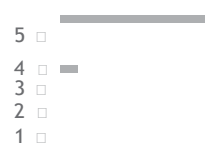
More funding for consumer vendored services and programs and better salaries for case managers. Minimum wage salaries for vendors results in low quality programs & high staff turnover. Better wages for case managers will promote dedicated staff.
November 14, 2022

4.1 ▢▢▢▢▢ (9 ▢)
Ranked #4 of 11

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Improve Communication There isn't always a lot of consistency across the RC's. Directives and language used in grants/grant measures is very vague and confusing.

November 14, 2022

4.0 ⬜⬜⬜⬜⬜ (9 ⬜)

Ranked #5 of 11

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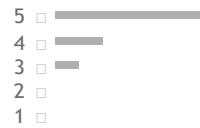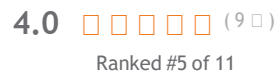
Interpretation & Translation We need more interpretation and translation agencies, funded by SDRC to improve service acceptance and utilization

November 14, 2022

4.0 ⬜⬜⬜⬜⬜ (7 ⬜)

Ranked #6 of 11

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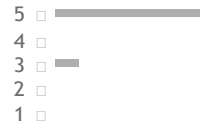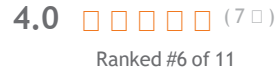
Limited the grants that serve statewide/multiple counties, or at least make sure they have the capacity to serve people in their catchment areas Several CBOs said they will serve multiple counties/state wide but not really do it, they only focus on some areas, then why put it in the grants.

November 14, 2022

4.0 ⬜⬜⬜⬜⬜ (6 ⬜) Ranked #7 of 11

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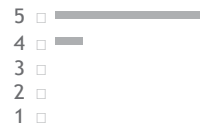
Looking at how not every program fits every family. Focusing on funding more programs with diversity and inclusion. Funding more CBO that are looking at disparities in our catchment area.

November 14, 2022

3.9 ⬜⬜⬜⬜⬜ (9 ⬜)

Ranked #8 of 11

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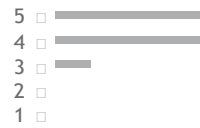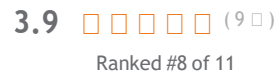
Prioritize more of the SAE funding towards the RC's programs Some of the programs we have seen funded in the past for other orgs are not connecting the community to our services

November 14, 2022

3.9 ⬜⬜⬜⬜⬜ (8 ⬜) Ranked #9 of 11

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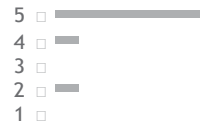
More direct interactions with CBOs, especially those with languages other than English. Connecting with Clients is the first step and educating them about available services and resources is what needs to happen next.

November 14, 2022

3.8 ⬜⬜⬜⬜⬜ (8 ⬜)

Ranked #10 of 11

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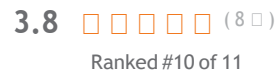
Many, however, at this time, just one. Find a way for the system to keep track of genetic resources. It will help us know what services someone receives, funded or not funded by the RC system, and look at equity, specifically where the needs are.

November 14, 2022

3.6 ⬜⬜⬜⬜⬜ (6 ⬜)

Ranked #11 of 11
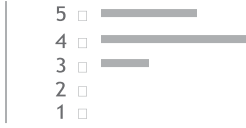
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Georgetown University

Q1 How does your Regional Center define equity for the population of people with IDD and their families?

Equal access to services and supports and equal outcomes for everyone and elimination of barriers to accessing services and supports An important aspect of outcomes is similarity in expenditures and the elimination of gaps in expenditures due to race, culture or language
December 13, 2022

3.8 □ □ □ □ □ (7 □)

Ranked #1 of 7

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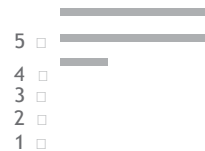
Equity-Providing the supports and services an individual and family needs Each individual has their own needs and barriers to overcome. Equity allows us to meet individuals where they are and support them
December 13, 2022

3.7 □ □ □ □ □ (7 □)

Ranked #2 of 7

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We define equity as providing services that are individualized and centered around each person's needs and preferences. We know that everyone has different access to resources, supports, and information, and some individuals and families need more support.
December 13, 2022

3.7 □ □ □ □ □ (7 □)

Ranked #3 of 7

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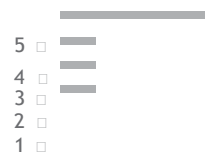
For everyone to have their needs met as they would like. People deserve to receive support how they best prefer it regardless of race, gender, sexuality, and culture.
December 13, 2022

3.6 □ □ □ □ □ (7 □)

Ranked #4 of 7

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Services are available and accessed by all ethnicities served by the agency. The individual needs of clients are met and barriers are mitigated. For fairness and to ensure that nobody is left behind in the developmental disability system.
December 13, 2022

3.6　☐☐☐☐☐　(7 ☐)
Ranked #5 of 7

5 ☐
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Access to and utilization of services that meets their individual needs Individuals with IDD should have equal access to opportunities for supports and services to live the life they choose
December 13, 2022

3.5　☐☐☐☐☐　(5 ☐)
Ranked #6 of 7

5 ☐
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Same start
December 13, 2022

3.2　☐☐☐☐☐　(4 ☐)
Ranked #7 of 7

5 ☐
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Georgetown University

Q2 How would you describe the root causes or factors that contribute to disparities in California's system for personswith IDD and their family members from racially, ethnically, culturally, and linguistically diverse backgrounds?

The California population was 92% White in the 1960s. The social construction of the law was premised on the White population of the State. We need to know why the disparities continue. Services and supports need to evolve to accommodate the need of the CLD population.
December 13, 2022

3.8 (7)
Ranked #1 of 11

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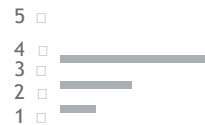
The system fails to address Cultural and linguistic diversity. Rates prevent competitiveness of tenderized service providers. High caseloads for SC Accessibility is a great issue. Not enough services available that are culturally and linguistically accessible
December 13, 2022

3.8 (7)
Ranked #2 of 11

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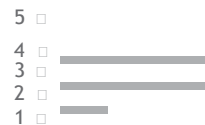
The service delivery system was created 50 years ago, and a lot has changed for persons with IDD and services since then. System needs to evolve. Through my work with the RC, I've learned of several factors that contribute to disparity such as limited understanding of RC system.
December 13, 2022

3.7 (4)
Ranked #3 of 11

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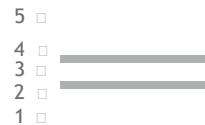
As with most systems the system for people with IDD was built for and to address the needs of white people/families, racially and culturally white With that understanding we can better build and refocus to include other people and cultures.
December 13, 2022

3.6 ▢▢▢▢▢ (6 ▢)
Ranked #4 of 11

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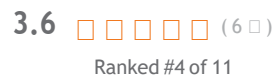
There is fear of speaking up and sharing individual needs. Fear of repercussion for accepting services needed. There are many barriers to overcome that are shared by individuals and families. System needs to be responsive to the needs and provide support
December 13, 2022

3.6 ▢▢▢▢▢ (6 ▢)
Ranked #5 of 11

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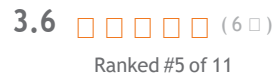
There are many causes- one of many causes is the lack of understanding about service options due to language barriers and lack access to information Individuals need information in order to make appropriate informed choices.
December 13, 2022
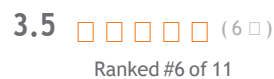
3.5 ▢▢▢▢▢ (6 ▢)
Ranked #6 of 11

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Racial discrimination
December 13, 2022

3.3 ▢▢▢▢▢ (7 ▢)
Ranked #7 of 11

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Racial discrimination.
December 13, 2022

3.3 ▢▢▢▢▢ (7 ▢)
Ranked #8 of 11

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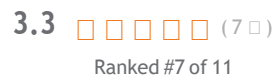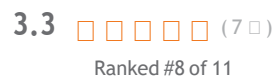
The implementation of WIC 4519.5 should pave the way for evolve services This is the law the allows all service access and equity activities.
December 13, 2022
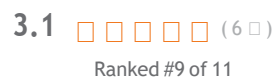
3.1 ▢▢▢▢▢ (6 ▢)
Ranked #9 of 11

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Georgetown University

Q3 What do you view as the role of the Cultural Specialist indisparities reduction in the California IDD system?

Cultural specialists should lead regional centers in efforts toward inclusion and diversity. Lead in identifying systemic barriers and addressing them Regional centers depend on the efforts of cultural specialist. The specialists go out in the community, hear people, participate in outreach.
December 13, 2022

4.0 ☐☐☐☐☐ (7 ☐)
Ranked #1 of 8

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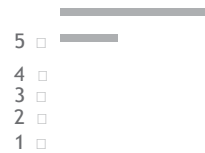
Bridging the regional center and DDS with diverse populations. Be an active listener with underserved populations and validate their struggles. Advocate for change that ends the disparities in expenditures
December 13, 2022

3.9 ☐☐☐☐☐ (7 ☐)
Ranked #2 of 8

5 ☐
4 ☐
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Inform RC and DDS on needs within our communities. Provide recommendations in partnership with individuals and families. Encourage people to use voice Being a bridge for people to voice their thoughts and needs in a safe space while being a bridge for RC to the state to address disparities
December 13, 2022

3.8 ☐☐☐☐☐ (7 ☐)
Ranked #3 of 8

5 ☐
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Identify the disparities and address barriers to accessing services and supports. Be a resource and connection point for underserved communities Without a focused and critical view of current system much needed change and growth will not happen.
December 13, 2022

3.7 ☐☐☐☐☐ (7 ☐)
Ranked #4 of 8

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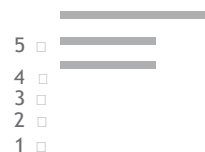
provide information to our community, listen to our community, and learn from our community apply info learned to make services more accessible and humanize the system to make it more approachable
December 13, 2022

3.7 ☐☐☐☐☐ (7 ☐)
Ranked #5 of 8

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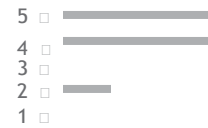
Share information w/regional center, share community voice and concerns. implement strategies to increase access and equity throughout regional center Important to maintain this issue as priority and be consistent. Important to work together and share success stories and what is or is not working.
December 13, 2022

3.5 ☐☐☐☐☐ (3 ☐)
Ranked #6 of 8

5 ☐
4 ☐
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Coordinate professional development, manage grants for service equity
December 13, 2022

3.3 ☐☐☐☐☐ (7 ☐)
Ranked #7 of 8

5 ☐
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The specialists are often ignored in the system. Effective specialists should have conversations with management and push for reforms. This is the mandate of the WIC 4519.5. Cultural specialists play a big role in its enforcement.
December 13, 2022

3.3 ☐☐☐☐☐ (4 ☐)
Ranked #8 of 8

5 ☐
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Georgetown University

Q4 How have you been involved in the Service Access and Equity (SAE) grant program in your Regional Center?

Planning meetings, grant writing, grant development, **Project Manager**, **project coordinator, report writer, billing reporting, organize, analyze, outrea** The ability to have the connection with members in the community, RC directors, and developing a project to address needs is imperative
December 13, 2022

4.0 ☐ ☐ ☐ ☐ ☐ (7 ☐)
Ranked #1 of 8

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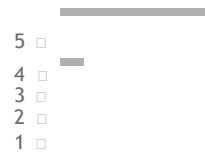
I oversee all the SAE grants- implementation, monitoring and reporting Important for one person to lead the effort to ensure consistency
December 13, 2022

3.9 ☐ ☐ ☐ ☐ ☐ (7 ☐)
Ranked #2 of 8

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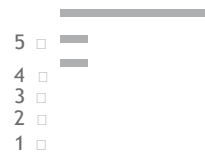
I served as Community Outreach Specialist (SAE grant), and oversaw Parent Mentor Program (SAE grant)
December 13, 2022

3.8 ☐ ☐ ☐ ☐ ☐ (7 ☐)
Ranked #3 of 8

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I was the primary person in charge of conceptualizing projects, writing them, and managing the implementation if approved. For innovative projects to be funded. Without the efforts, we will not have funded projects.
December 13, 2022

3.8 ☐ ☐ ☐ ☐ ☐ (7 ☐)
Ranked #4 of 8

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Read directive. Coordinated meetings with directors. Created positions. Developed budget and followed up on implementation. Service equity...in general. The grants may not have been utilized had we not taken initiative to create, develop and implement
December 13, 2022

3.8 ☐☐☐☐☐ (7 ☐)
Ranked #5 of 8

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Reporting, applying for and reviewing CBO grants. Also coordinating work with consultants and assistants. Ensuring underserved/diverse client feedback and needs are centered and addressed represented with projects and grand proposals.
December 13, 2022

3.8 ☐☐☐☐☐ (7 ☐)
Ranked #6 of 8

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In my experience, our RC was completely dependent on me as the specialist for all SAE grant projects Little support provided in managing multiple projects at one time.
December 13, 2022

3.7 ☐☐☐☐☐ (6 ☐)
Ranked #7 of 8

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Implemented projects in the past. Currently maintain communication and provide support to more than 20 CBOs implementing projects in our RC Area I'm a member of several committees that offer support to CBOs implementing projects in our catchment area
December 13, 2022

3.6 ☐☐☐☐☐ (3 ☐)
Ranked #8 of 8
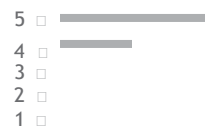
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Georgetown University

Q5 What recommendations do you have for DDS about disparities reduction?

Listen to each RC's needs. Equity driven listening and responsiveness to each RC. Review and understand each RC's disparities (not all the same) Each RC has similar yet additional needs to provide support to the communities.
December 13, 2022

3.8 (6)
Ranked #1 of 9

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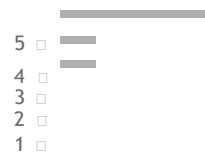
Lack of available services (culturally and linguistically appropriate) is a huge problem. Need to increase rates to meet service needs Quantity and quality of appropriate and diverse services is imperative! Huge shortage of services and even less for non-english speaking individuals
December 13, 2022

3.8 (4)
Ranked #2 of 9

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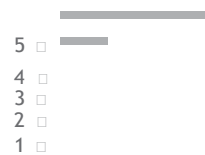
materials/information translated and available in as many languages as possible;stronger presence in community and collab with RCs on presentations communicate expectations using various methods and ensure understanding
December 13, 2022

3.7 (6)
Ranked #3 of 9

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DDS to encourage regional centers to start vendoring projects that have worked for the CLD population In order for the CLD population to access services, whatever service that has been implemented and found successful should become an ongoing service
December 13, 2022

3.7 (5)
Ranked #4 of 9

5
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Encourage stronger collaboration between regional centers and CBOs. Successful SAE grant projects to become a vendored service available for all CLD populations.
December 13, 2022

3.7 ☐☐☐☐☐ (5 ☐)
Ranked #5 of 9

5 ☐
4 ☐
3 ☐
2 ☐
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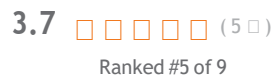
Fund direct services that are accessible culturally and linguistically. Extend funding for at least 2 years. Let RCs award the funds to CBOs in area Instead of centralizing the decision making process in Sacramento funds should strengthen regional centers' ability to work with CBOs in their area
December 13, 2022

3.7 ☐☐☐☐☐ (5 ☐)
Ranked #6 of 9

5 ☐
4 ☐
3 ☐
2 ☐
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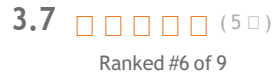
Continuing the trend of centering clients and the diverse/underserved communities in out respective RC catchments Clients understand best what their needs are and what is priority for themselves.
December 13, 2022

3.5 ☐☐☐☐☐ (7 ☐)
Ranked #7 of 9

5 ☐
4 ☐
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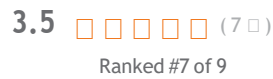
DDS to meet with directors and cultural specialists at least once per quarter to clarify responsibilities and who's doing what by when. Consistency
December 13, 2022

3.5 ☐☐☐☐☐ (7 ☐)
Ranked #8 of 9

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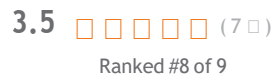
Consistency is important
December 13, 2022

3.3 ☐☐☐☐☐ (7 ☐)
Ranked #9 of 9

5 ☐
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ThoughtExchange
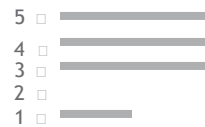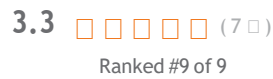
Appendix G

Listening Session Summary: Community Based Organization(CBO) Staff

Georgetown University

Q1 How would you describe the root causes or factors that contribute to disparities in California's system for personswith intellectual and developmental disabilities (IDD) and their family members from racially, ethnically, culturally and linguistically diverse backgrounds?

Lack of linguistically and culturally competent service provider to support the minority groups, so even if they have POS, they can't use it. Because families who have limited English capacity need to be able to communicate with their service provider in their home language.
Thursday, December 08, 2022

4.1 (10)
Ranked #1 of 20

5
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Trust Lack of trust for government organizations hinders relationship and outcomes
Thursday, December 08, 2022

4.1 (10)
Ranked #2 of 20

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1

Systemic Racism, Lack Strategic and Directed Outreach, Ignorance and disregard of cultural differences, Management/Leadership in ability to lead We live in a world that difference is the majority. It not that we need to be experts in a culture but we do need to know how to be responsive
Thursday, December 08, 2022

4.1 (9)
Ranked #3 of 20

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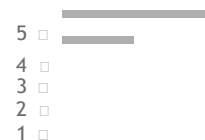
There needs to be more materials that are culturally relevant and representative of communities, More cultural understanding, patience and flexibility To build trust with families and make safe spaces for them. Empower them more to help move their families forward
Thursday, December 08, 2022

4.1 ☐ ☐ ☐ ☐ ☐ (8 ☐)

Ranked #4 of 20

5 ☐
4 ☐
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Implicit Bias that evolve into judgements due to lack of information, thereby prohibiting services. We cannot provide person centered services effectively without understanding the person and potential trauma influenced communication.
Thursday, December 08, 2022

4.0 ☐ ☐ ☐ ☐ ☐ (11 ☐)

Ranked #5 of 20

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐

Language Barriers Available service providers that meets their needs
Thursday, December 08, 2022

4.0 ☐ ☐ ☐ ☐ ☐ (11 ☐)

Ranked #6 of 20

5 ☐
4 ☐
3 ☐
2 ☐
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Cultural Different cultures feel intimidated by RC, organizations etc which impacts the outcome
Thursday, December 08, 2022

4.0 ☐ ☐ ☐ ☐ ☐ (10 ☐)

Ranked #7 of 20

5 ☐
4 ☐
3 ☐
2 ☐
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racism many government systems were set up without valuing or considering the needs of all people (especially black and brown people and people with IDD
Thursday, December 08, 2022

4.0 ☐ ☐ ☐ ☐ ☐ (8 ☐)

Ranked #8 of 20

5 ☐
4 ☐
3 ☐
2 ☐
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Systemic racial capitalism It is not being addressed
Thursday, December 08, 2022

4.0 ☐ ☐ ☐ ☐ ☐ (6 ☐)

Ranked #9 of 20

5 ☐
4 ☐
3 ☐
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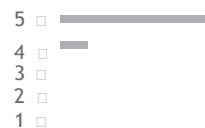
Language Language is critical to learning, communication and navigating the system.
Thursday, December 08, 2022

3.9 ☐ ☐ ☐ ☐ ☐ (10 ☐)

Ranked #10 of 20

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4 ☐
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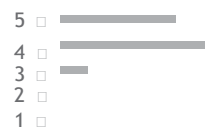
Unfair treatment , couldn't provide best vulnerable environment Lack of empathies
Thursday, December 08, 2022

3.9 (10)
Ranked #11 of 20

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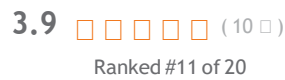
implicit bias, cultural and linguistical misunderstandings and reactions not addressed without understanding of the clients' cultural and linguistic background , it's impossible for the regional centers to meet their needs and services
Thursday, December 08, 2022

3.9 (9)
Ranked #12 of 20

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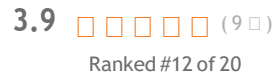
overly complex and uneccessary paperwork families have to complete paperwork over and over again for each agency, there should be one statewide application that is simple and easy to navigate
Thursday, December 08, 2022

3.9 (9)
Ranked #13 of 20

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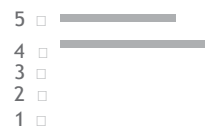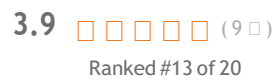
difficulty finding providers/supports that are linguistically or culturally concordant
Thursday, December 08, 2022

3.9 (6)
Ranked #14 of 20

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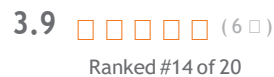
Technology Access to technology - we have successful sessions in Zoom but community is accessing through laptops/desktops, phones and tablets - navigation differ
Thursday, December 08, 2022

3.8 (10)
Ranked #15 of 20

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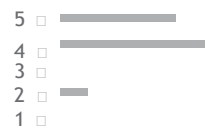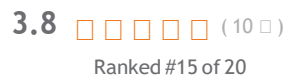
Language Materials not provided and presented in preferred language - eg SSI forms in English only!
Thursday, December 08, 2022

3.8 (9)
Ranked #16 of 20

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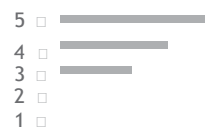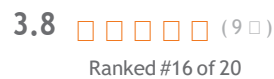
The regional center system in CA has been historically organized around the needs of white middle class families with children with I/DD. This created structural barriers to participation in the system for anyone who is not white and middle class.
Thursday, December 08, 2022

3.7 (10)
Ranked #17 of 20

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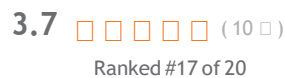
With flexibility and patience from services to go outside the "9-5" norm. Many families will be able to access more assistance not all families can come to an evaluation at noon, they miss work and can't go back or lose a days pay.
Thursday, December 08, 2022

3.6 ☐ ☐ ☐ ☐ ☐ (6 ☐)

Ranked #18 of 20

5 ☐
4 ☐
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systems that support people with IDD overlap with systems that specifically harm people with IDD, esp. black and brown and undocumented people if families feel a system will harm them they do not want to participate
Thursday, December 08, 2022

3.6 ☐ ☐ ☐ ☐ ☐ (6 ☐)

Ranked #19 of 20

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐

It helpful
Thursday, December 08, 2022

2.7 ☐ ☐ ☐ ☐ ☐ (9 ☐)

Ranked #20 of 20

5 ☐
4 ☐
3 ☐
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Georgetown University

Q2 List up to three successes achieved by your Service Access and Equity (SAE) grant project.

Provide opportunity for unique projects that cater to specific underserved communities reaching these communities can close the gap in disparities
Thursday, December 08, 2022

4.0 ☐☐☐☐☐ (11 ☐)
Ranked #1 of 19

5 ☐
4 ☐
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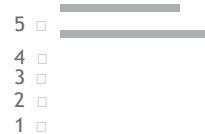
1) Increased families' awareness and knowledge on regional center services, 2) More families applying for RC intake, 3) empower parents to advocate The more the families know about services, the more willing they will be to request for the services
Thursday, December 08, 2022

4.0 ☐☐☐☐☐ (9 ☐)
Ranked #2 of 19

5 ☐
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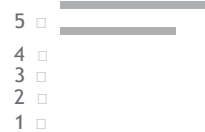
We have been able to begin addressing the issue of employment within the IDD community via the grant after hearing the need from participants. We partnered with Amazon and it was an immediate outcome with 4-6 SDRC clients receiving employment across the county.
Thursday, December 08, 2022

4.0 ☐☐☐☐☐ (9 ☐)
Ranked #3 of 19

5 ☐
4 ☐
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2 ☐
1 ☐

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1. hearing/serving Black families concerns at the grassroots level 2. getting the ear of leaders at the system level 3. collaboration w/ Black orgs rebuilding the village that has been dismantled by racism and ableism and ignorance
Thursday, December 08, 2022

3.9 ☐☐☐☐☐ (11 ☐)
Ranked #4 of 19

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐

Creating materials for families to understand in their proper variant and language. Some materials were once non existent Expands materials for all to use also.
Thursday, December 08, 2022

3.9 ☐☐☐☐☐ (11 ☐)
Ranked #5 of 19

5 ▬▬▬▬▬
4 ▬▬▬▬
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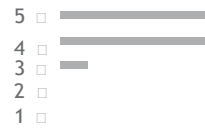
Expand the inventory of individual service provider; connect family with service providers; Educate public on culture competence.
Thursday, December 08, 2022

3.9 ☐☐☐☐☐ (11 ☐)
Ranked #6 of 19

5 ▬▬▬▬▬
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We have centered the experiences and voices of our most vulnerable families and are paying them for their expertise Families need to be fairly compensated for their expertise in identifying and addressing the barriers to services.
Thursday, December 08, 2022

3.9 ☐☐☐☐☐ (11 ☐)
Ranked #7 of 19

5 ▬▬▬▬▬
4 ▬▬▬
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Language Language delivery both orally & in materials has helped bridge understanding & outcomes for individuals and families. Helping to increase engagement.
Thursday, December 08, 2022

3.9 ☐☐☐☐☐ (10 ☐)
Ranked #8 of 19

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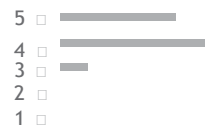
The most impacted families are identifying what our agency and the regional center can do differently to better support their communities. Our agency will use the recommendations families make to make changes to our programming and we will share their recommendations with the RC
Thursday, December 08, 2022

3.9 ☐☐☐☐☐ (9 ☐)
Ranked #9 of 19

5 ▬▬▬▬
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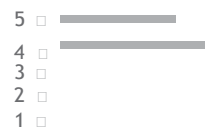
Trusted organization Meeting our participants where they are at and helping to improve outcomes. Collaborating together, providing a forum to share and learn is helping
Thursday, December 08, 2022

3.9 ☐☐☐☐☐ (9 ☐)
Ranked #10 of 19

5 ▬▬▬▬
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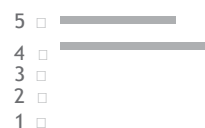
1) Retain bilingual bicultural staff, 2) develop linguistically and culturally competent program capacity 3) outreach to those with no or low POS Reduce disparity and increase access to programs
Thursday, December 08, 2022

3.9 (8)

Ranked #11 of 19

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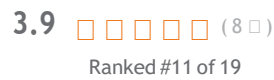
Collaborating with families to make outreach materials more accessible to our target communities RC info is not accessible
Thursday, December 08, 2022

3.9 (8)

Ranked #12 of 19

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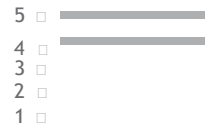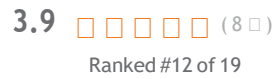
Services, Culture & Language needs
Thursday, December 08, 2022

3.8 (11)

Ranked #13 of 19

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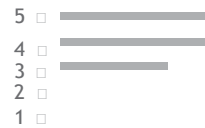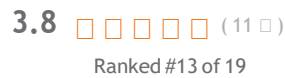
We have now successfully engages in partnership with the San Diego County Indigenous Community and looking forward to some great outcomes. This is one of our majorly underserved populations.
Thursday, December 08, 2022

3.8 (10)

Ranked #14 of 19

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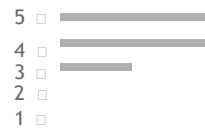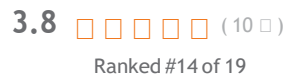
30 + parent - run CBOs have been supported at different stages of development; we assisted with their work (TA and mentorship) during the pandemic The majority of the CBOs are run by African American mothers of children with IDD; a tailored program was developed to support their work.
Thursday, December 08, 2022

3.8 (8)

Ranked #15 of 19

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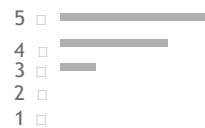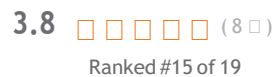
Cascade Impact Helping educate caregivers/families and Self-Advocates who are cascading that knowledge through their respective communities, through a "trusted" rep.
Thursday, December 08, 2022

3.7 (10)

Ranked #16 of 19

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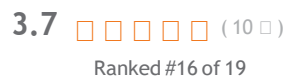
We are gaining visibility in the community and found the medical area partnerships that help educate new parents about services. Broadens our reach.
Thursday, December 08, 2022

3.7 (8)

Ranked #17 of 19

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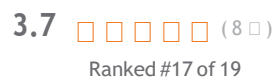
educate and advocate families that still believe this is a taboo theme and should not be talked about. Sharing testimonies and narratives counterstorytelling is the impact
Thursday, December 08, 2022

3.6 ☐☐☐☐☐ (11 ☐)
Ranked #18 of 19

5 ☐ ▬▬▬
4 ☐ ▬▬▬▬
3 ☐ ▬▬
2 ☐
1 ☐ ▬

The CBOs provide services to thousands of families in historically disinvested areas. We aimed to increase their capacity to serve these communities. This created a very localized, culturally affirming approach to SAE.
Thursday, December 08, 2022

3.4 ☐☐☐☐☐ (4 ☐)
Ranked #19 of 19

5 ☐ ▬▬▬
4 ☐ ▬▬▬▬
3 ☐ ▬▬
2 ☐
1 ☐

Georgetown University

Q3 List up to three barriers encountered in implementingyour SAE grant project.

Low paying job in the field is hard to attract trained individual to work
Thursday, December 08, 2022

4.2 ☐☐☐☐☐ (8 ☐)
Ranked #1 of 19

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐

New Service Coordinators not trained effectively and they will answer questions with a no or incorrect response. This has left many not pursuing support further. Promotes more distrust.
Thursday, December 08, 2022

4.1 ☐☐☐☐☐ (10 ☐)
Ranked #2 of 19

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐

Scheduling conflicts between service and family, language access, empathy working outside of the normal office hours is a must for certain communities
Thursday, December 08, 2022

4.1 ☐☐☐☐☐ (10 ☐)
Ranked #3 of 19

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐

Non engaged or changing Service Coordinators without notice. Decrease trust.
Thursday, December 08, 2022

4.1 ☐☐☐☐☐ (9 ☐)
Ranked #4 of 19

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐

Hiring It is challenging in todays climate to hire team members.
Thursday, December 08, 2022

4.0 ☐☐☐☐☐ (9 ☐)
Ranked #5 of 19

5 ☐
4 ☐
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1-year grant cycle is too short Not enough time to build sustainable long-term change
Thursday, December 08, 2022

3.9 ▢▢▢▢▢ (10 ▢)
Ranked #6 of 19

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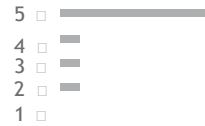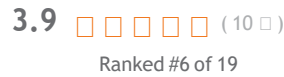
Regional Center staff are not well trained, delays in POS or eligibility approval, huge discrepancy between regional centers The clients don't receive the services they need
Thursday, December 08, 2022

3.9 ▢▢▢▢▢ (9 ▢)
Ranked #7 of 19

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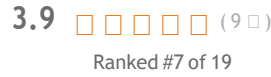
communication between CBO and regional center can be difficult. Asking for information about trainings or seminars has been ignored. its important to know the process of it all in order to also help families and explain to them what to expect
Thursday, December 08, 2022

3.9 ▢▢▢▢▢ (9 ▢)
Ranked #8 of 19

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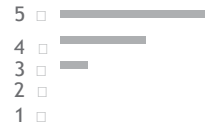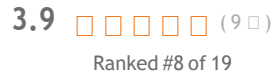
technology access and understanding, transportation needs for services provided, explanation of child diagnosis evaluations are also stressful for the parents and if you cant read/write or speak english you feel alone at times
Thursday, December 08, 2022

3.9 ▢▢▢▢▢ (9 ▢)
Ranked #9 of 19

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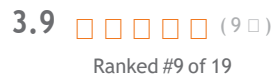
Lack of trust from families initially and misinformation from the families' case manager/service coordinators
Thursday, December 08, 2022

3.9 ▢▢▢▢▢ (6 ▢)
Ranked #10 of 19

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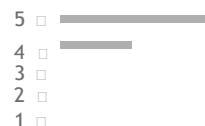
Technology Everyone accesses technology via different mechanisms
Thursday, December 08, 2022

3.8 ▢▢▢▢▢ (9 ▢)
Ranked #11 of 19

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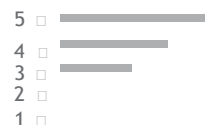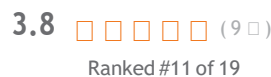
Black Community: So much historical damage lack of trust of the "system" Difficult to reach physically/emotionally. RC equate # served to significanc e Because Black Lives Matter even if the # of RC Black clients are low. Less doesn't mean insignificant
Thursday, December 08, 2022

3.8 ▢▢▢▢▢ (8 ▢)
Ranked #12 of 19

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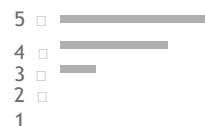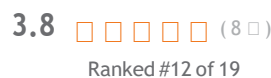
service coordinators who can work with family schedule or meet outside of an office space. needs to build trust.
Thursday, December 08, 2022

3.8 ☐☐☐☐☐ (8 ☐)

Ranked #13 of 19

5 ☐
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Education, Culture and Language
Thursday, December 08, 2022
translated by Google

3.8 ☐☐☐☐☐ (7 ☐)

Ranked #14 of 19

5 ☐
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Families not feeling comfortable signing DDS consent form Our communities do not trust systems
Thursday, December 08, 2022

3.7 ☐☐☐☐☐ (9 ☐)

Ranked #15 of 19

5 ☐
4 ☐
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Covid
Thursday, December 08, 2022
translated by Google

3.6 ☐☐☐☐☐ (9 ☐)

Ranked #16 of 19

5 ☐
4 ☐
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Service coordinators specifically unfamiliar with the African American population promoting insensitivity. Promoting lack of trust that anyone cares or will do anything to help.
Thursday, December 08, 2022

3.6 ☐☐☐☐☐ (8 ☐)

Ranked #17 of 19

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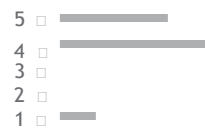
Priorities Everyone is "strapped" for time & balancing competing priorities
Thursday, December 08, 2022

3.5 ☐☐☐☐☐ (10 ☐)

Ranked #18 of 19

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COVID has presented a significant challenge; attendance of some of our workshops due to other commitments has been lower than we wished We found solutions to address these challenges by recording all the workshops and providing resources for managing during the pandemic
Thursday, December 08, 2022

3.5 ☐☐☐☐☐ (8 ☐)

Ranked #19 of 19

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Georgetown University

Q4 How would you describe the effectiveness of your SAEgrant project in increasing equity?

Created a community Provided opportunity for community to collaborate and learn together to improve outcomes for ALL.
Thursday, December 08, 2022

3.9 ☐☐☐☐☐ (9 ☐)
Ranked #1 of 12

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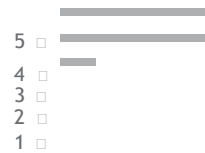
Migrant indigenous families are no longer isolating themselves and can build support and community with other families in similar situations belonging and community are powerful
Thursday, December 08, 2022

3.9 ☐☐☐☐☐ (9 ☐)
Ranked #2 of 12

5 ☐
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We are assisting non English and or Spanish speaking migrant indigenous community. Provide information utilizing the promotora model Sharing space with people who have already gone through the process you are about to go through impacts the case.
Thursday, December 08, 2022

3.9 ☐☐☐☐☐ (9 ☐)
Ranked #3 of 12

5 ☐
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provide high quality service
Thursday, December 08, 2022

3.9 ☐☐☐☐☐ (9 ☐)
Ranked #4 of 12

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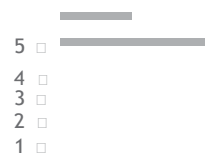
Accessibility Accessibility increased access to knowledge and delivery from a trusted party helped level information and increase equity.
Thursday, December 08, 2022

3.8 ☐☐☐☐☐ (10 ☐)
Ranked #5 of 12

5 ☐
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Moderate - We work hard to promote equity but the systems is not doing the best job to really maintain the change Black community deserves to be treated with Love Dignity and Respect

Thursday, December 08, 2022

3.8 ☐☐☐☐☐ (9 ☐)

Ranked #6 of 12

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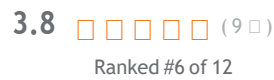
Creating safe spaces for parents to speak about their concerns, at times on zoom while not fully interrupting their everyday routine. having zoom meeting during dinner prep and see a mom make handmade tortillas and answer questions about her experiences. That is still professional

Thursday, December 08, 2022

3.8 ☐☐☐☐☐ (8 ☐)

Ranked #7 of 12

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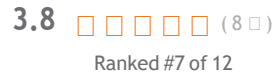
Organization is collaborating as authentic partners Those closest to the problem are closest to solution

Thursday, December 08, 2022

3.7 ☐☐☐☐☐ (9 ☐)

Ranked #8 of 12

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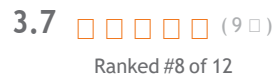
The SAE project has been serving more CBOs that are able to serve more families in part due to our TA and mentorship program Effectiveness-wise we are doing the best we can under the pandemic and other structural inequities conditions

Thursday, December 08, 2022

3.7 ☐☐☐☐☐ (9 ☐)

Ranked #9 of 12

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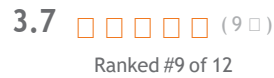
Not so effective because equity in POS lies in the hands of the regional centers not with the CBOs. Can't hire staff without enough RC funding

Thursday, December 08, 2022

3.6 ☐☐☐☐☐ (9 ☐)

Ranked #10 of 12

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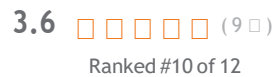
it create an opportunity for organization in the community to work on these issues! Issues are easy to talk about, but hard to solve. the grant is really allowing organizations to take action to improve the situation and improve it.

Thursday, December 08, 2022

3.6 ☐☐☐☐☐ (9 ☐)

Ranked #11 of 12

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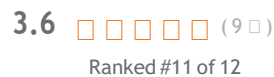
Very effective. We have outreached to close to 1000 families and educated several hundreds of them on services and advocacy Helps the families understand the services they are entitled to and how they can access them.

Thursday, December 08, 2022

3.3 ☐☐☐☐☐ (2 ☐)

Ranked #12 of 12
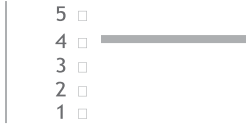
5 ☐
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Georgetown University

Q5 How would you describe the effectiveness of your SAE grant project in decreasing disparities?

Improved access and education in "core" language and culturally appropriate Helped community to access services and supports to help decrease disparity.
Thursday, December 08, 2022

4.0 ☐☐☐☐☐ (9 ☐)
Ranked #1 of 14

5 ☐
4 ☐
3 ☐
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Somewhat effective. We not only train qualified individual to provide service in our targeted population, as well as train family members to provide proper care.
Thursday, December 08, 2022

4.0 ☐☐☐☐☐ (8 ☐)
Ranked #2 of 14

5 ☐
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As multiple people have already stated - these small grants alone cannot address the disparities inherent in the system
Thursday, December 08, 2022

3.9 ☐☐☐☐☐ (9 ☐)
Ranked #3 of 14

5 ☐
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Different measurements of success, making sure needs are catered to the family and not just a checklist. every case is different and all approaches matter
Thursday, December 08, 2022

3.9 ☐☐☐☐☐ (9 ☐)
Ranked #4 of 14

5 ☐
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Outreach to families has been a success, meeting them where they are having conversations with community at 4am when they go get their pan and cafe. We are there.
Thursday, December 08, 2022

3.9 ☐☐☐☐☐ (9 ☐)
Ranked #5 of 14

5 ☐
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my mission of my org is to decrease disparities and increase access. we increase access to information that lead families to make informed decisions the key to access is literally the key to a life full of choices, freedom and opportunities
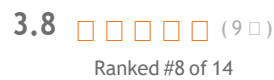*Thursday, December 08, 2022*

3.9 ⬜⬜⬜⬜⬜ (8 ⬜)
Ranked #6 of 14

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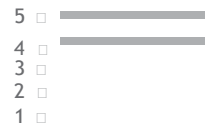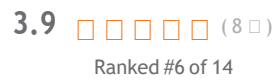
advocacy on language access not only in spanish but in indigenous languages
Thursday, December 08, 2022

3.8 ⬜⬜⬜⬜⬜ (9 ⬜)
Ranked #7 of 14

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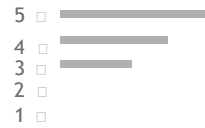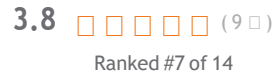
creating materials in indigenous languages and explaining what certain IDD are in order for families to be educated Materials are not just flyers but also radio and FB live programming
Thursday, December 08, 2022

3.8 ⬜⬜⬜⬜⬜ (9 ⬜)
Ranked #8 of 14

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The creation of a trusted village resulted in exchange and sharing of information
Thursday, December 08, 2022

3.8 ⬜⬜⬜⬜⬜ (8 ⬜)
Ranked #9 of 14

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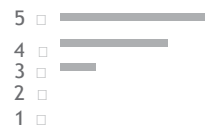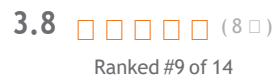
We did not evaluate specific decreases in POS disparities; we did evaluate increased capacity of programs that increase access to services Methodologically, it is difficult to evaluate 'decreasing disparities'. We used National Core Indicators surveys to evaluate experiences with services
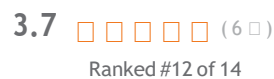*Thursday, December 08, 2022*

3.8 ⬜⬜⬜⬜⬜ (8 ⬜)
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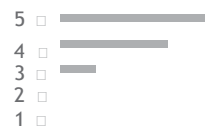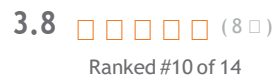
Development between individuals, families, service providers
Thursday, December 08, 2022

3.7 ⬜⬜⬜⬜⬜ (8 ⬜)
Ranked #11 of 14

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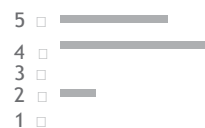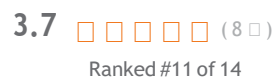
Successful in educating our families to access services, but due to other factors, families were still without services
Thursday, December 08, 2022

3.7 ⬜⬜⬜⬜⬜ (6 ⬜)
Ranked #12 of 14

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educational videos on a weekly bases for families to access anytime.
Thursday, December 08, 2022

3.6 ☐☐☐☐☐ (8 ☐)

Ranked #13 of 14

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not reimbursed competitive wage without that can't increase capacity and reduce disaparity
Thursday, December 08, 2022

3.6 ☐☐☐☐☐ (8 ☐)

Ranked #14 of 14

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Georgetown University

Q6 Thinking of the statewide SAE grant program, what two recommendations for quality improvement would you suggest to the Department of Developmental DisabilitiesServices?

Make the duration of the grants longer than one year. It has been very difficult to plan and implement programs based upon a 12 months cycle. It would improve effectiveness of the SAE funding program to make a maximal impact
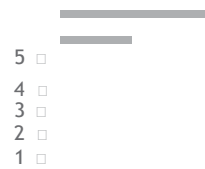*Thursday, December 08, 2022*

4.1 (10)
Ranked #1 of 10

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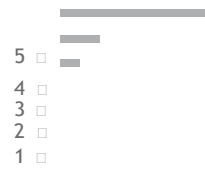
Mandate that RC implement community recommendations - stop acting as gatekeepers, make process simpler, get back to families on time, etc
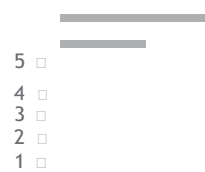*Thursday, December 08, 2022*

4.1 (9)
Ranked #2 of 10

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1) Ensure service coordinators are well-trained 2) More funding for bilingual staff so they can support bilingual clients
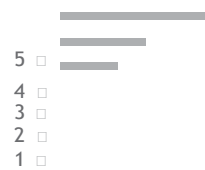*Thursday, December 08, 2022*

4.0 (8)
Ranked #3 of 10

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Guidelines or suggestions for better relationship between CBO and RC CBO have different goals that meet community not a system
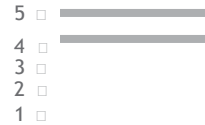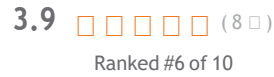*Thursday, December 08, 2022*

3.9 (10)
Ranked #4 of 10

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Check ins with RC and all CBO grantees in same area? At times the list of resources is gatekept and if we all have same goal we should all collaborate together
*Thursday, December 08, 2022*

3.9 (9)
Ranked #5 of 10

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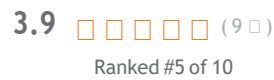
Consistent Regional Center engagement varies across 21 but the partnership in sharing information is critical to success.
Thursday, December 08, 2022

3.9 (8)
Ranked #6 of 10

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Grant Vantage implementation in recent years has been great and DDS is very responsive in support but... Microsoft needs to make some improvements in ease of use, to help us use more effectively.
Thursday, December 08, 2022

3.8 (9)
Ranked #7 of 10

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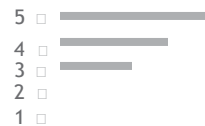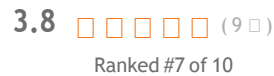
Improve RC's staff training in services & SAE. Increase reimbursement for service providers that provide quality ling. & cult, competent programs
Thursday, December 08, 2022

3.8 (8)
Ranked #8 of 10

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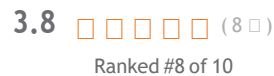
reorganizing the the structure of DDS and it's relationship to RC. There is NO ACCOUNTABILITY NO COMPETITION WITH RC so why would they do the right DDS contracts with RCs its a financial relationship and not clear accountability relationships it makes it difficult to enforce system changes
Thursday, December 08, 2022

3.8 (8)
Ranked #9 of 10

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4
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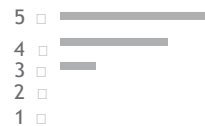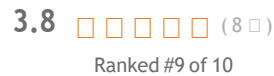
Provide service and languages support
Thursday, December 08, 2022
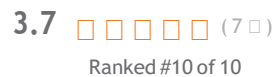
3.7 (7)
Ranked #10 of 10

5
4
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Georgetown University

Q1 How would you describe the root causes or factors that contribute to disparities in California's system for personswith intellectual and developmental disabilities (IDD) and their family members from racially, ethnically, culturally and linguistically diverse backgrounds?

Difficulty navigating the system. Confusing information. Lack of central system. People don't understand what is available or how to access services.
Friday, December 09, 2022

4.4 (12) Ranked
#1 of 21

5
4
3
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1

There is a structure that requires families to ASK for services, but families do not necessarily know what those are. They are not offered services
Friday, December 09, 2022

4.3 (12) Ranked
#2 of 21

5
4
3
2
1

lack of cultural understanding Caseworkers need to understand the dynamics which may be affecting a family including cultural differences, language, socioeconomic status.
Friday, December 09, 2022

4.3 (12) Ranked
#3 of 21

5
4
3
2
1

Families do not understand the Regional Center system and services available Easy to understand information provided in multiple languages, formats by trusted messengers is needed re services and accessing services.

4.3 (10) Ranked
#4 of 21

5
4
3
2
1

Historical ignorance of different races/ethnicities/linguistic diversity Long-standing mindsets are difficult to undo
Friday, December 09, 2022

4.2 ☐☐☐☐☐ (12 ☐)

Ranked #5 of 21

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐

Lack of culturally sensitive case managers and service providers and implicit bias If case managers bring implicit biases to their work, disparities are perpetuated.
Friday, December 09, 2022

4.2 ☐☐☐☐☐ (12 ☐)

Ranked #6 of 21

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐

Services are not all culturally responsive.
Friday, December 09, 2022

4.2 ☐☐☐☐☐ (12 ☐)

Ranked #7 of 21

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐

Staffing - within regional centers and providers Low wages and high turnover contribute to a lack of available services and support.
Friday, December 09, 2022

4.2 ☐☐☐☐☐ (12 ☐)

Ranked #8 of 21

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐
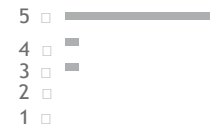
Systems barriers, many families simply do not have the phone, internet, and computer access or health literacy required to make it through applying
Friday, December 09, 2022

4.2 ☐☐☐☐☐ (12 ☐)

Ranked #9 of 21

5 ☐
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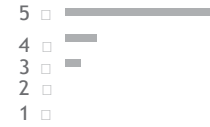
Understanding systems, obtaining information in their primary language and trainings in the families primary language. Because the language and system processes are so complex, the need to present the information in the families primary language is necessary.
Friday, December 09, 2022

4.2 ☐☐☐☐☐ (12 ☐)

Ranked #10 of 21

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐

Language barriers Families do not know what derives are available because the information is not readily available in their language
Friday, December 09, 2022

4.2 ☐☐☐☐☐ (11 ☐)

Ranked #11 of 21

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐

The Regional Center being payor of last resort causes families to be bounced back and forth between medical insurance, schools, and the RC many families give up. There is no one central to help them get through this - unless created through other programs
Friday, December 09, 2022

4.2 ☐☐☐☐☐ (11 ☐)
Ranked #12 of 21

5 ▬▬▬▬
4 ▪
3 ▪
2 ☐
1 ☐
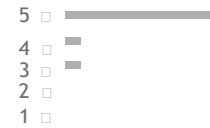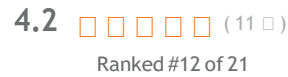
Systems barriers It is very difficult for many families to access the system. There are multiple barriers related to required applications and documentation
Friday, December 09, 2022

4.1 ☐☐☐☐☐ (12 ☐)
Ranked #13 of 21

5 ▬▬▬▬
4 ▬▬
3 ▪
2 ☐
1 ☐

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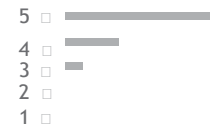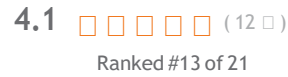
culture differences, language barriers, lack of knowledge and information
Friday, December 09, 2022

4.1 ☐☐☐☐☐ (12 ☐)
Ranked #14 of 21

5 ▬▬▬▬
4 ▬
3 ▬
2 ☐
1 ☐
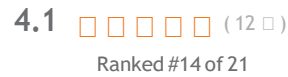
Information is not always vailable on the people primary language, RC staff and provider do not provide information in the primary language. Inmy area there is a large number of monolingual familes whose their primary language is not English
Friday, December 09, 2022

4.1 ☐☐☐☐☐ (10 ☐)
Ranked #15 of 21

5 ▬▬▬▬
4 ▪
3 ▪
2 ☐
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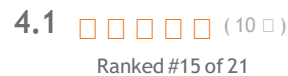
Language access understanding rights and services
Friday, December 09, 2022

4.1 ☐☐☐☐☐ (10 ☐)
Ranked #16 of 21

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4 ▪
3 ▪
2 ☐
1 ☐
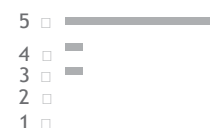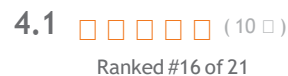
Too much bureaucracy
Friday, December 09, 2022

3.9 ☐☐☐☐☐ (12 ☐)
Ranked #17 of 21

5 ▬▬▬▬
4 ▬▬
3 ▪
2 ▪
1 ☐

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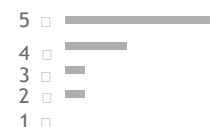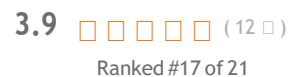
lack of outcome measures on unmet needs Currently there is no mechanism to capture and analyze data to determine specific needs of families (ie Spanish speaking respite providers, etc)
Friday, December 09, 2022

3.9 ☐☐☐☐☐ (11 ☐)
Ranked #18 of 21

5 ▬▬▬▬
4 ▬▬▬
3 ▬
2 ☐
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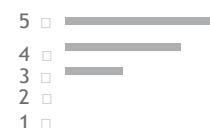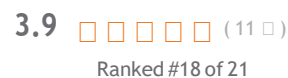
Fast-growing areas of the State; policies, procedures, beliefs take a while to change This HAS TO change. Even today, we (my center) needs to advocate for families whose children clearly are eligible and appropriate RC clients
Friday, December 09, 2022

3.8 ☐ ☐ ☐ ☐ ☐ (11 ☐)

Ranked #19 of 21

5 ▬▬▬▬
4 ▬▬▬
3 ▬▬
2 ☐
1 ☐

Poverty and income disparities, especially for people with IDD and their families. Lack of sensitivity by professionals & providers to the true needs and conditions of people with IDD (e.g., tech apps that discriminate as this one?)
Thursday, December 08, 2022

0.0 ☐ ☐ ☐ ☐ ☐ (0 ☐)

Ranked #20 of 21

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐

Too few providers ready to serve the needs
Thursday, December 08, 2022

0.0 ☐ ☐ ☐ ☐ ☐ (0 ☐)

Ranked #21 of 21

5 ☐
4 ☐
3 ☐
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Georgetown University

Q2 List up to three successes achieved by your Service Access and Equity (SAE) grant project.

Forming deep relationships with individuals, families, and regional center. Expanding our expertise.
Friday, December 09, 2022

4.0 (10)
Ranked #1 of 21

5
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Internal staffing structure of specialists to meet the needs of the Spanish speaking individuals and families we support.
Friday, December 09, 2022

4.0 (10)
Ranked #2 of 21

5
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1. Increased referrals from our regional center, 2. joint RC/FRC family presentations, 3. increased bilingual staff capacity to support families A collaborative approach with the RC allows us to support families better, having more bilingual navigators allows us to better serve families facing
Friday, December 09, 2022

4.0 (9)
Ranked #3 of 21

5
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Ensures collaboration to develop educational material that all Latino leaders have access to Material available in English and Spanish
Friday, December 09, 2022

4.0 (9)
Ranked #4 of 21

5
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In addition to public dissemination of information, we have had one-on-one personal contact with some families to provide individual mentoring. Each individual content provides "case examples" to guide development of future project goals.
Friday, December 09, 2022

4.0 (9)
Ranked #5 of 21

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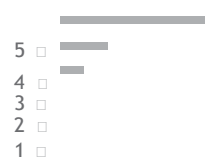
More collaboration and connection within the various nonprofits serving the Latino/Spanish speaking community we are better and stronger together
Friday, December 09, 2022

4.0 ☐☐☐☐☐ (9 ☐)
Ranked #6 of 21

5 ☐
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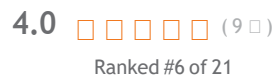
Providing adult transition information in Spanish (presenter speaks Spanish). Conference for Black families of kids with special needs. Meeting families where they are. Culturally sensitive. Presenter speaking Spanish is preferred to interpretation.
Friday, December 09, 2022

4.0 ☐☐☐☐☐ (9 ☐)
Ranked #7 of 21

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐
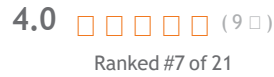
Translating materials into Spanish. Working with families to learn Zoom.
Friday, December 09, 2022

4.0 ☐☐☐☐☐ (9 ☐)
Ranked #8 of 21

5 ☐
4 ☐
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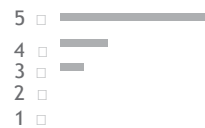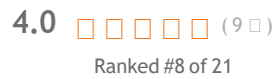
Created a navigator program that provided direct assistance to families with regional center applications/connection in a pediatric clinic setting
Friday, December 09, 2022

3.9 ☐☐☐☐☐ (9 ☐)
Ranked #9 of 21

5 ☐
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1 ☐
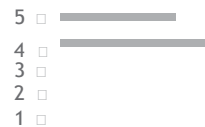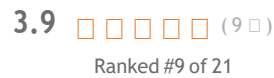
The navigator program revealed how much difficulty families face and how much advocacy is needed to get any services
Friday, December 09, 2022

3.9 ☐☐☐☐☐ (9 ☐)
Ranked #10 of 21

5 ☐
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3 ☐
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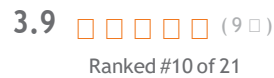
This program allowed my organization to better understand the barriers families face on a daily basis and advocate for change
Friday, December 09, 2022

3.9 ☐☐☐☐☐ (9 ☐)
Ranked #11 of 21

5 ☐
4 ☐
3 ☐
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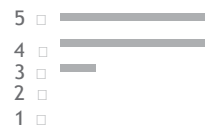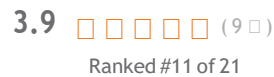
Latino community is at the table The last four four years has enabled us to build a collaborative which now has relationships with policymakers.
Friday, December 09, 2022

3.8 ☐☐☐☐☐ (10 ☐)
Ranked #12 of 21

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐
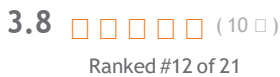
We have adapted information dissemination to the times (e-based during Covid) so successfully that we have continued that medium. Because Inland Southern California is such a vast region, in-person events, by their very nature, can exclude families who need them most.
Friday, December 09, 2022

3.8 ▢▢▢▢▢ (9 ▢)
Ranked #13 of 21

5 ▢
4 ▢
3 ▢
2 ▢
1 ▢

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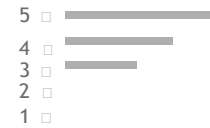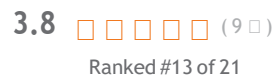
training on various topics, social gathering activities, and help parents speak out providing more training to parents to update their knowledge about the system and all other things. Social activities will bring the share knowledge
Friday, December 09, 2022

3.8 ▢▢▢▢▢ (4 ▢)
Ranked #14 of 21

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2 ▢
1 ▢
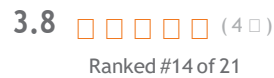
Formation of the ongoing DEI Taskforce and creation of the organization's inclusiveness blueprint.
Friday, December 09, 2022

3.7 ▢▢▢▢▢ (10 ▢)
Ranked #15 of 21

5 ▢
4 ▢
3 ▢
2 ▢
1 ▢
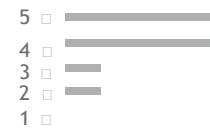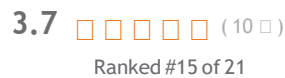
Support group for parents, awareness and access to RCOC services Parents needs support from their peers
Friday, December 09, 2022

3.7 ▢▢▢▢▢ (9 ▢)
Ranked #16 of 21

5 ▢
4 ▢
3 ▢
2 ▢
1 ▢

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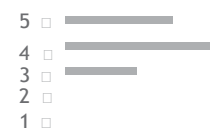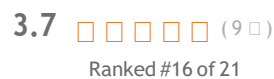
1) meaningful, ongoing engagement but regional center leadership around DEI, 2) localized DEI solutions for a regional center built by the community.. Change implemented and sustained through changed policies and ongoing practices
Friday, December 09, 2022

3.6 ▢▢▢▢▢ (9 ▢)
Ranked #17 of 21

5 ▢
4 ▢
3 ▢
2 ▢
1 ▢
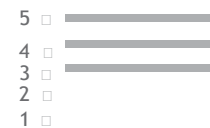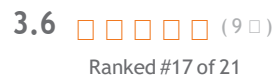
We have met some amazing professionals and families from all areas of the IE. Collaboration and cooperation now leads the way to the future.
Friday, December 09, 2022

3.6 ▢▢▢▢▢ (5 ▢)
Ranked #18 of 21

5 ▢
4 ▢
3 ▢
2 ▢
1 ▢
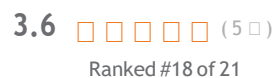
increased the 3 of Vietnamese and Hispanic families served 1:1 - Host conferences and workshops with spa and viet translation. Created SDP support gro Families do not have to travel to long distances to get the help they need. We can help with papers and connectingup
Friday, December 09, 2022

3.2 ☐☐☐☐☐ (1 ☐)
Ranked #19 of 21

5 ☐
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3 ☐
2 ☐
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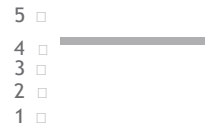
Created a way for Service Coordinators and families to problem-solve culturally-rooted concerns together, in real-time This helps reduce the blame and finger pointing and helps staff and families trust each other more.
Thursday, December 08, 2022

0.0 ☐☐☐☐☐ (0 ☐)
Ranked #20 of 21

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐

Created a way for our Hmong families to interact 1-on-1 with Service Coordinators The Service Coordinators and families seldome have a chance to get to know each other as people, outside of the client relationship
Thursday, December 08, 2022

0.0 ☐☐☐☐☐ (0 ☐)
Ranked #21 of 21

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐

Georgetown University

Q3 List up to three barriers encountered in implementingyour SAE grant project.

Having to re-apply for funding every year is difficult, we hardly have a chance to get started before doing the application for the next year.
Friday, December 09, 2022

4.2 ☐☐☐☐☐ (10 ☐)
Ranked #1 of 23

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐

Not enough time/funds given to see real impact Hard to see real impact in a 1-2 year project which is hard to renew.
Friday, December 09, 2022

4.2 ☐☐☐☐☐ (9 ☐)
Ranked #2 of 23

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐

Difficult collaborating with Regional Centers - understaffing, lack of systems and data
Friday, December 09, 2022

4.1 ☐☐☐☐☐ (10 ☐)
Ranked #3 of 23

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐

Hiring team members, RC intake timelines, Service Coordinator and provider turnover Having consistent support staff for families assists in building trust.
Friday, December 09, 2022

4.1 ☐☐☐☐☐ (10 ☐)
Ranked #4 of 23

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐
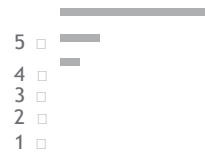
Initially received some pushback from the Regional Centers - this has improved over time and they now see us as partners.
Friday, December 09, 2022

4.1 ☐☐☐☐☐ (10 ☐)
Ranked #5 of 23

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐

The amount of data we are expected to collect on each family can create barriers - instead of spending more time helping families, our navigators are spending excessive time doing surveys and documenting results.
Friday, December 09, 2022

4.1 □□□□□ (10 □)
Ranked #6 of 23

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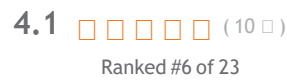
Approval of reporting, working with RC and not enough time to implement project until another reapplication is due Time should be spent working with the community
Friday, December 09, 2022

4.1 □□□□□ (9 □)
Ranked #7 of 23

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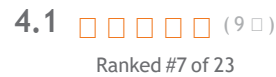
Wildfires, pandemic. Daily crisis for regional centers made it difficult to work on DEI, which was reprioritized to less urgent times
Friday, December 09, 2022

4.1 □□□□□ (9 □)
Ranked #8 of 23

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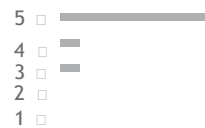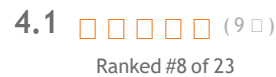
For grants over 100k, funds are reimbursed after the quarterly reports are approved which could take 6 months. Need more efficient reporting and reimbursement model - change the dollar amount to $250k for reimbursement
Friday, December 09, 2022

4.0 □□□□□ (9 □)
Ranked #9 of 23

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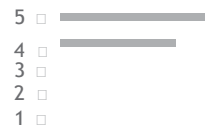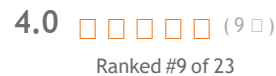
Reporting is time consuming
Friday, December 09, 2022

4.0 □□□□□ (7 □)
Ranked #10 of 23

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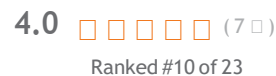
Virtual platforms are difficult for Spanish speaking families - complex registration & access. Often using a phone
Friday, December 09, 2022

4.0 □□□□□ (7 □)
Ranked #11 of 23

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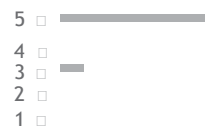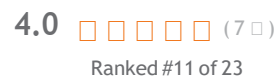
Getting other agencies, and even the local RC, to help with publicity for events. Getting participation on webinars, panels and other virtual events is critical.
Friday, December 09, 2022

3.9 □□□□□ (10 □)
Ranked #12 of 23

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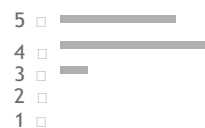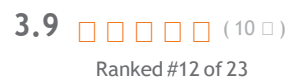
Metrics are not consistent. Some can be cumbersome.
Friday, December 09, 2022

3.9 ☐☐☐☐☐ (10 ☐)

Ranked #13 of 23

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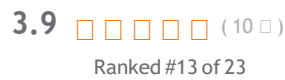
Difficult completing project in 12 months
Friday, December 09, 2022

3.9 ☐☐☐☐☐ (9 ☐)

Ranked #14 of 23

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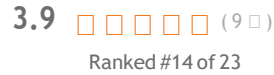
Re-budgeting is overly cumbersome, and the time it takes to do that we could be doing more work in the community. Time spent on administrative tasks is time not reaching the families who are underserved.
Friday, December 09, 2022

3.9 ☐☐☐☐☐ (9 ☐)

Ranked #15 of 23

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Receiving feedback in the way that works best for families without intimidation.
Friday, December 09, 2022

3.9 ☐☐☐☐☐ (9 ☐)

Ranked #16 of 23

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gather parents to attend the training, technology knowledge that parents are willing to learn
Friday, December 09, 2022

3.9 ☐☐☐☐☐ (9 ☐)

Ranked #17 of 23

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Resistance from the rc Collaboration
Friday, December 09, 2022

3.8 ☐☐☐☐☐ (5 ☐)

Ranked #18 of 23

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3 ☐
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Changing an established culture System needs to evolve
Friday, December 09, 2022

3.7 ☐☐☐☐☐ (4 ☐)

Ranked #19 of 23

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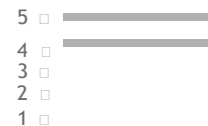
Quarterly reports and reporting platform are cumbersome and very time consuming.
Friday, December 09, 2022

3.7 ☐☐☐☐☐ (4 ☐)

Ranked #20 of 23

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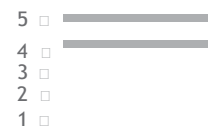
Lack of central focus at beginning of grant program.
Friday, December 09, 2022

3.6 ☐ ☐ ☐ ☐ ☐ (10 ☐)

Ranked #21 of 23

5 ☐
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Implement new and current systems of service and collaboration Needs to be more collaborative and inclusive
Friday, December 09, 2022

3.4 ☐ ☐ ☐ ☐ ☐ (2 ☐)

Ranked #22 of 23

5 ☐
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High rotation of Service coordinators and lack of training. Poor collaboration with the Regional Center. No culturally competent services
Friday, December 09, 2022

3.2 ☐ ☐ ☐ ☐ ☐ (1 ☐)

Ranked #23 of 23

5 ☐
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Georgetown University

Q4 How would you describe the effectiveness of your SAEgrant project in increasing equity?

I feel that we have continued to build the trust of families to assist them in advocating to assess services and navigate systems. It is important to educate and help families build advocacy skills so that they feel comfortable in accessing services for their child.
Friday, December 09, 2022

4.2 (10) Ranked #1 of 20

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Our project increased equity by being able to bring families in to the Regional Center system who otherwise would not have been able to jump through the many hoops of applying for and obtaining services. Some families need help just getting an email address to access this new tech based-world
Friday, December 09, 2022

4.2 (10) Ranked #2 of 20

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The model increased equity by being able to provide support individual's in the language they prefer.
Friday, December 09, 2022

4.1 (10) Ranked #3 of 20

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There are other outcomes besides an increase of POS Families need information to access other systems and services. The grant does not capture and report out to the legislators other outcomes.
Friday, December 09, 2022

4.1 (10) Ranked #4 of 20

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parents understand more about the IPP and how to talk and request more services for their children with I/DD and sharing knowledge among the parents
Friday, December 09, 2022

4.1 ☐☐☐☐☐ (9 ☐)

Ranked #5 of 20

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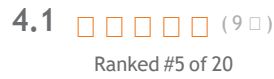
we have improved equity of sharing material, information, resources, but hard to gauge effectiveness in accessing services. We can get families to the table, but we cant force RC to provide services.
Friday, December 09, 2022

4.1 ☐☐☐☐☐ (9 ☐)

Ranked #6 of 20

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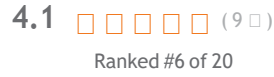
Continuos interaction By continuing to engage with families and as a community we stay in top of relevant issues and topics. Can interact and engage in real-time
Friday, December 09, 2022

4.0 ☐☐☐☐☐ (10 ☐)

Ranked #7 of 20

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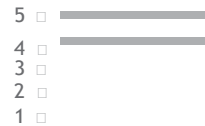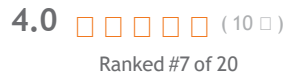
Creating an inclusiveness blueprint to evaluate DEI through the whole organization.
Friday, December 09, 2022

4.0 ☐☐☐☐☐ (10 ☐)

Ranked #8 of 20

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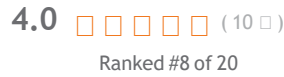
Very strong based on relationship building Our approach is to establish a relationship with families and rc staff and grow from that point.
Friday, December 09, 2022

4.0 ☐☐☐☐☐ (10 ☐)

Ranked #9 of 20

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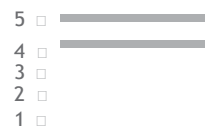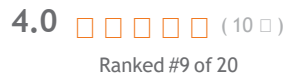
Providing service provider staff with the same implicit bias and language access training RC staff receive.
Friday, December 09, 2022

4.0 ☐☐☐☐☐ (9 ☐)

Ranked #10 of 20

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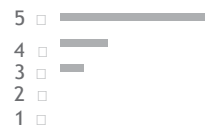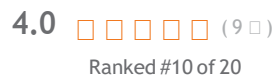
We have established ourselves as a trusted messenger for families.
Friday, December 09, 2022

3.9 ☐☐☐☐☐ (10 ☐)

Ranked #11 of 20

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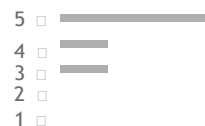
We have increasing numbers of Spanish-speaking families at our events and utilizing our services. This is one of our project goals.
Friday, December 09, 2022

3.9 (10)
Ranked #12 of 20

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Short term, very effective. But change takes time. They should be 2 or 3 year grants
Friday, December 09, 2022

3.7 (10)
Ranked #13 of 20

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Uniting community and defining voice By connecting with the key source we are able to address issues and help obtain solutions in a more timely manner
Friday, December 09, 2022

3.7 (8)
Ranked #14 of 20

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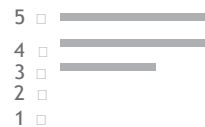
At many events, more than half of our participants are Spanish-speaking and are recipients of important information about transitions. This is another important aspect of outreach.
Friday, December 09, 2022

3.7 (7)
Ranked #15 of 20

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Still have a long way to go, pandemic created bigger challenges that we are still figuring out with the I/DD community
Friday, December 09, 2022

3.7 (7)
Ranked #16 of 20

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To our eyes, we have increased equity. We can see it in the families we serve. But, we need access to accurate data from the RC to see the results.
Friday, December 09, 2022

3.7 (4)
Ranked #17 of 20

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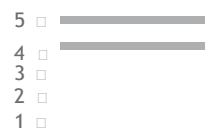
increasing and improve I/DD children's cognitive through social activities
Friday, December 09, 2022

3.6 (10)
Ranked #18 of 20

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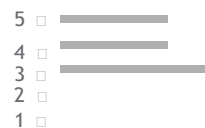
To be honest, this program has no reliable metric for this.
Friday, December 09, 2022

3.5 (6)
Ranked #19 of 20

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Our project allowed opportunities to help service coordinators better understand cultural and linguistic barriers their families face. Our navigators often had to act as culture brokers, or mediators, and inform service coordinators they were not using a families preferred language
Friday, December 09, 2022

3.3 ☐☐☐☐☐ (6 ☐)
Ranked #20 of 20
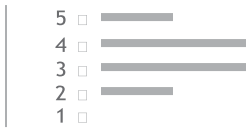
5 ☐
4 ☐
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Georgetown University

Q5 How would you describe the effectiveness of your SAEgrant project in decreasing disparities?

Our community has awaken and is now asking to be part of the process As Mr Carruthers testified yesterday we are in the midst of hyper-reform within our system
Friday, December 09, 2022

4.2 ▢▢▢▢▢ (9 ▢)
Ranked #1 of 15

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Family empowerment: Increasing knowledge about IDD/autism and service access for underrepresented families. This is a key goal of the program.
Friday, December 09, 2022

4.1 ▢▢▢▢▢ (9 ▢)
Ranked #2 of 15

5 ▢
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We targeted a large pediatric clinic where the majority of patients are Latino/hispanic and generated hundreds of new referrals to the Regional center and helped families gain additional resources through the RC, thus we did directly target the disparity in POS for Latino families
Friday, December 09, 2022

4.1 ▢▢▢▢▢ (9 ▢)
Ranked #3 of 15

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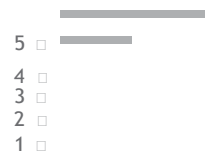
help parents to understand better the RC and the system It is very important that parents understand the RC services and how to communicate to RC to obtain services
Friday, December 09, 2022

4.1 ▢▢▢▢▢ (9 ▢)
Ranked #4 of 15

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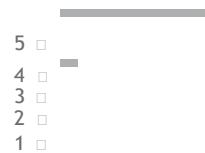
The model decreased disparities by creating a link and liaison between families, providers, and regional centers. It helped individuals and families access the services that they need.
Friday, December 09, 2022

4.0 ▢▢▢▢▢ (9 ▢)
Ranked #5 of 15

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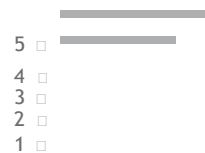
Help parents to speak out and describe what they want to RC and others
Friday, December 09, 2022

3.9 □□□□□ (9 □)
Ranked #6 of 15

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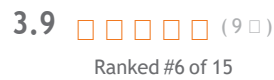
We were effective in families indicating their knowledge increased about adult transition options, topics & felt like they could better advocate.
Friday, December 09, 2022

3.9 □□□□□ (9 □)
Ranked #7 of 15

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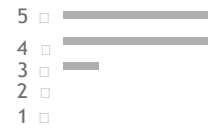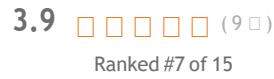
Wider scope of impact. Our project has exceeded our expectation of increasing collaboration and knowledge about the RC system for the Latino community and other systems.
Friday, December 09, 2022

3.9 □□□□□ (9 □)
Ranked #8 of 15

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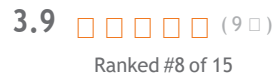
Able to decrease from the degree that we have influence. Still challenged by systemic barriers.
Friday, December 09, 2022

3.8 □□□□□ (9 □)
Ranked #9 of 15

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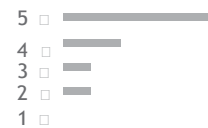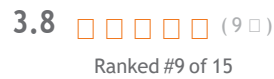
Strong but we went from barriers, to roadblock to now what we see as a slippery sloop Definition of disparities and what they really are have evolved and the system needs to better understand these changes
Friday, December 09, 2022

3.8 □□□□□ (9 □)
Ranked #10 of 15

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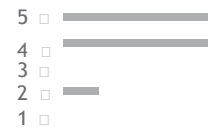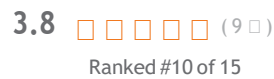
We were able to reach more families and assist them in obtaining and utilizing RC and generic services. Families who have a child with IDD were not connected to RC services or needed assistance obtaining generic services due to many challenges.
Friday, December 09, 2022

3.8 □□□□□ (9 □)
Ranked #11 of 15

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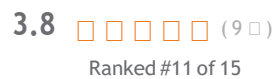
By maintaining a relationship with families we can address new barriers and challenges as they present themselves Eliminate the barriers that create disparities.
Friday, December 09, 2022

3.8 □□□□□ (7 □)
Ranked #12 of 15

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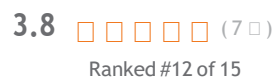
As has been said, really hard to move the needle on RC or DDS system disparities because of the length of time for the projects.
Friday, December 09, 2022

3.7 ☐☐☐☐☐ (9 ☐)

Ranked #13 of 15

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Community has access to in language materials and know your rights
Friday, December 09, 2022

3.6 ☐☐☐☐☐ (5 ☐)

Ranked #14 of 15

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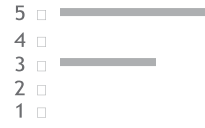
We will need accurate data from RC to measure the effectiveness We have done everything in the grants to be effective in reducisng disparity.
Friday, December 09, 2022

3.5 ☐☐☐☐☐ (5 ☐)

Ranked #15 of 15

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1

Georgetown University

Q6 Thinking of the statewide SAE grant program, what two recommendations for quality improvement would you suggest to the Department of Developmental DisabilitiesServices?

Longer time for the project instead of 1 year if possible
Friday, December 09, 2022

4.3 ☐☐☐☐☐ (9 ☐)

Ranked #1 of 24

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐

Reporting due every 6 months, instead of every quarter. Lengthen time of project to 2-3 years to really give CBOs a chance for greatest impact
Friday, December 09, 2022

4.3 ☐☐☐☐☐ (9 ☐)

Ranked #2 of 24

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐

Longer funding periods
Friday, December 09, 2022

4.2 ☐☐☐☐☐ (9 ☐)

Ranked #3 of 24

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐

Allow for more two-three year grants with 90% funding up front up to $250k
Friday, December 09, 2022

4.1 ☐☐☐☐☐ (9 ☐)

Ranked #4 of 24

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐

Develop ways to increase the network among grantees. Grouping projects and creating networks of support during implementation.
Friday, December 09, 2022

4.1 ☐☐☐☐☐ (9 ☐)

Ranked #5 of 24

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐

Longer grant periods of at least 3 years
Provide Grantees the opportunity and ability to grow their project.
Friday, December 09, 2022

4.1 ☐☐☐☐☐ (9 ☐)

Ranked #6 of 24

5 ▬▬▬▬
4 ▬▬
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Longer project periods and different metrics for reporting Long term impact and sustainability efforts
Friday, December 09, 2022

4.1 ☐☐☐☐☐ (9 ☐)

Ranked #7 of 24

5 ▬▬▬▬
4 ▬
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Make reporting simpler
Friday, December 09, 2022

4.1 ☐☐☐☐☐ (9 ☐)

Ranked #8 of 24

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Simplify Reporting Process Possibly change reporting requirements to every 6 months, ensure outcome measures are priorities.
Friday, December 09, 2022

4.1 ☐☐☐☐☐ (9 ☐)

Ranked #9 of 24

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Streamline the reporting process and make it easier to report Takes a tremendous amount of effort to meet reporting requierments
Friday, December 09, 2022

4.1 ☐☐☐☐☐ (9 ☐)

Ranked #10 of 24
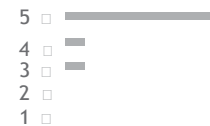
5 ▬▬▬▬
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3 ▪
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The application and reporting can be a large barrier to smaller organizations participating There could be an opportunity to expand by providing a smaller funding opportunity that is aimed at smaller organizations with a simplified process.
Friday, December 09, 2022

4.1 ☐☐☐☐☐ (9 ☐)

Ranked #11 of 24

5 ▬▬▬▬
4 ▪
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Do not fund any more regional center requests for mandated SAE activities, like translations or specialized service coordinators. Pay through Ops!
Friday, December 09, 2022

4.0 ☐☐☐☐☐ (9 ☐)

Ranked #12 of 24

5 ▬▬▬▬
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3 ▪
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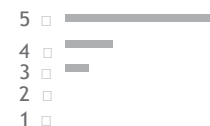
Longer grant timelines. Develop trainings for RC teams utilizing the data and info gathered from CBOs work. The work and data gathered by CBO in the community reflect the needs of the families being served, needs to be shared!
Friday, December 09, 2022

4.0 ☐☐☐☐☐ (9 ☐)

Ranked #13 of 24

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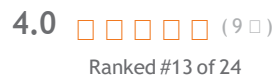
Standardized measures, with some flexibility would be helpful with reporting and comparing data.
Friday, December 09, 2022

4.0 ☐☐☐☐☐ (9 ☐)

Ranked #14 of 24

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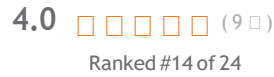
Continue the collaborative model with monthly presentations.
Friday, December 09, 2022

3.9 ☐☐☐☐☐ (9 ☐)

Ranked #15 of 24

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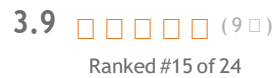
Fund innovative ideas that truly come from the community, not just the dominant culture thinking it knows what's best
Friday, December 09, 2022

3.9 ☐☐☐☐☐ (9 ☐)

Ranked #16 of 24

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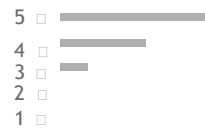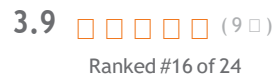
As mentioned by others, CBOs have done incredible work but for real, sustainable change, there needs to be changes on the RC level. There needs to be increased intake staff, higher wages for service coordinator to decrease turnover, and a cultural shift to that of trying to help.
Friday, December 09, 2022

3.9 ☐☐☐☐☐ (8 ☐)

Ranked #17 of 24

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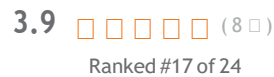
Cross pollinate efforts within projects that compliment each other Collaborative efforts
Friday, December 09, 2022

3.8 ☐☐☐☐☐ (9 ☐)

Ranked #18 of 24

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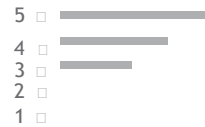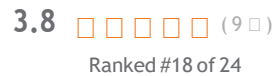
Incentivize more caseworker participation or learning opportunities available from the CBOs
Friday, December 09, 2022

3.6 ☐☐☐☐☐ (9 ☐)

Ranked #19 of 24

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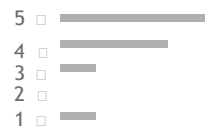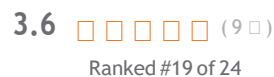
Look for grant ideas that transform the $12B system
Friday, December 09, 2022

3.6 ☐☐☐☐☐ (9 ☐)

Ranked #20 of 24

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐

Projects longer than one year to see real results - Improve CMR and reporting
Friday, December 09, 2022

3.6 ☐☐☐☐☐ (2 ☐)

Ranked #21 of 24

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐

Fund collaborations between agencies, with commensurate budget allocation. More synergy.
Friday, December 09, 2022

3.3 ☐☐☐☐☐ (1 ☐)

Ranked #22 of 24

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐

Grant programs for 2 to 3 years. Most programs need time to gear up and measure any outcomes.
Friday, December 09, 2022

3.3 ☐☐☐☐☐ (1 ☐)

Ranked #23 of 24

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐
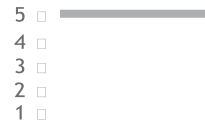
Improve metrics for Progress Reports -- simpler to input. Perhaps go back to a narrative, with a simple table all recipients have to complete. Important to be able to detect commonalities and successes across projects.
Friday, December 09, 2022

3.3 ☐☐☐☐☐ (1 ☐)

Ranked #24 of 24

5 ☐
4 ☐
3 ☐
2 ☐
1 ☐

Appendix H

Data Brief: Community Based Organization (CBO) Survey

Data Brief: Community Based Organizations (CBOs) Survey Findings

The findings from the CBO survey included an analysis of data from 34 respondents and their responses were categorized into the following groups: 1) description of SAE grant project design approaches, 2) outcomes achieved in availability, accessibility, acceptability, quality and utilization. and 3) reflections on implementation.

SAE Grant Project Design and Approaches

This section summarizes CBO survey respondents' descriptions of why they submitted a grant proposal, whether the project was designed to address disparities at the individual family, community and/or systems levels, and the strategies used to both design and to implement the grant.

Reasons for submitting a grant proposal

"The disparity for African American/Black Families is beyond what the numbers show. There is a disparity and injustice not only to families who are clients of the RC services but there is a lack of access to the information to even gain access into this system of care. The system seems to put this huge focus on linguistics as if that is the only disparity that exist."

When asked why their organization decided to submit a proposal to DDS for its SAE program, CBO grantees reported the following reasons: 1. to improve equity and accessibility of supports and services, 2. to focus on underserved communities that are unaware of or not receiving services, and 3. to obtain extra funding and resources to continue serving these populations.

Disparities reduction at varying levels

"The participant is educated on navigating from the perspective of an independent facilitator. This increases their knowledge for personal development and reduces disparities that they experience navigating the system, as they have the knowledge to successfully navigate. The cascade impact to the family and self-advocate is the improved quality of life from accessing services and supports."

According to the responses received, CBO grantees designed their projects to reduce disparities at various levels. At the individual and family levels, they worked to reduce disparities by providing education on how to access services. At the community level, CBO grantees planned to reduce disparities by organizing community events, building trust within communities, and creating opportunities for social networks.

At the systems level, CBO grantees designed projects to reduce disparities by providing training, partnering with other organizations, and incorporating feedback from families.

Use of culturally and linguistically competent approaches

"Our focus is on one cultural group. The leadership of the organization is of that culture and has been trained to serve the culture better in different aspects."

All CBO grantees reported that their project used both culturally and linguistically competent approaches to implement their grant. The approaches included hiring multicultural/ multilingual staff, providing cultural activities and services in languages other than English, using peer-to-peer models, and consulting members and experts.

Use of theory of change frameworks and logic models

"Our theory of change program design is based on engaging our community and uniting our voice by empowering individuals to be part of the process and solution."

When asked whether they used a theory of change framework for their SAE grant project, the majority, 55% of CBO grantees responded affirmatively. However, most did not list a specific framework, and those that did indicated that they used the following: The Promotora model, Emergent Theory, and Social Learning Theory. Reasons for not using a theory of change included not being aware of this concept.

When asked if they used a logic model to demonstrate the correlation between advancing equity and disparities reduction within their grant project, 45% reported "yes" that they had included a logic model, 39% reported that they did not, and 16% replied that they did not know if a logic model was used. Reasons for not using a logic model included that it wasn't requested, there were no experts available to help create one, and their approach cannot be modeled on a linear level.

Engagement of persons with IDD and their families

"We included surveys and conversation questions as way to gain feedback, evaluate progress, and identify priorities."

Most CBO grantees reported that they did engage persons with IDD and their families to evaluate the supports and services provided by their project. This was done through the use of feedback and collaboration/involvement of family members.

Data collection to document disparities reductions

"We collected qualitative data - individual stories, workshop surveys, and satisfaction surveys. Provider feedback and engagement surveys."

CBO grantees mentioned collecting data and documenting the progress of their projects through surveys/evaluations and purchase of services. Other data collected included social media interactions, data on barriers, demographics, programs, and translations and interpretations. When asked to report their current capacity for collecting, analyzing and reporting on disparities data, the majority of CBO grantees, 57% reported that their CBO had *moderate capacity*.

Strategies used to reach individuals and families that do not receive services

"We work with partners and their promotoras to do outreach to schools and other organizations in an area where the underserved community resides. (Name or information withheld for anonymity) never referred any new family for additional support"

"The new strategies help to increase the number of Hispanic and Vietnamese new cases. We were able to support and provide info to more families in person until the pandemic came…and we only were able to access few families for a long time"

Respondents were asked to describe the strategies used to reach individuals that are either unknown or not receiving services through the regional center. The most common strategy mentioned by CBO grantees was hosting outreach events and seminars. Other strategies included the use of social media, partnerships with organizations, such as other state and tribal agencies, and word of mouth. CBO grantees reported that these strategies resulted in new clients with increased trust and knowledge of services.

Outcomes Achieved

This section summarizes the outcomes achieved in availability, accessibility, acceptability, quality, and utilization.

Availability of supports and services

"The SAE grant enabled us to build capacity and increase our collaborative partners which in turn enabled us to provide better supports and services to our target population."

CBO grantees explained that the grant project increased the availability of supports and services through various means. Many grantees emphasized the importance of collaboration and support in increasing the availability of supports and services for the target populations. Availability was also increased by having more providers that represented the culture of the families served.

Accessibility of supports and services

"We mentored to families to assist them in accessing more generic and regional center services. We provide language interpretation and translation for families with limited English ability for our seminars, parent meetings and coffee socials. We provide in-person services as well as virtual services for those who have more difficulty traveling to a location. Some of the families that we do not have language capacity to support, we refer them to agencies who can support them."

A majority of CBO grantees reported that the accessibility of supports and services was significantly increased through their efforts. Activities that increased accessibility included family mentoring, language interpretation and translation, virtual services, and referrals to other agencies. Language accessibility in particular was emphasized. Bilingual project staff also helped families access services they were previously unaware of, and this commitment to improving language access helped outside agencies better serve families navigating the system.

Acceptability of supports and services

"We provided workshops to destigmatize cultural stigma and promote seeking help for families dealing with IDD family members. This helped increased acceptance to receive IDD training and providing support, as well as, asking for support."

Most respondents reported that their SAE grant project increased the acceptability of supports and services. This was generally achieved by cultivating and maintaining trust with families through linguistic and cultural competence.

Utilization of supports and services

"Although we serve mainly the Asian special needs population which has been increasing over the years, we have also increased the number of other ethnic groups such as the Hispanic population. We have more Hispanic clients than a few years before."

Most respondents reported that their SAE grant project increased utilization of supports and services. Several CBO grantees reported that they've seen an increase in the number of families from ethnic groups outside of their SAE grant population of focus.

Quality of supports and services

"One of the hallmarks of our program is the extraordinary quality of the programs that the CBOs provide. Uniformly, the CBO leaders pour their hearts and souls into the programs they develop. This places them apart from programs that run under business models."

Most CBO grantees responded that the SAE grant project increased the quality of supports and services. A shift toward a person-centered approach and utilizing knowledgeable staff who are both culturally and linguistically competent are a few examples of how the quality of supports and services has improved. A few grantees reported that their project did not improve the quality of supports and services, due to their project being focused on aspects other than quality.

Reflections on Implementation

In this section, respondents highlight the importance of SAE grants as part of efforts to reduce disparities in supports and services for persons with IDD, challenges and barriers in implementation, positive outcomes of the projects, and recommendations for improvement.

Importance of SAE grant in disparity reduction efforts

When asked to rate how important the SAE grant program is to their organization's efforts to decrease disparities among persons with IDD across racial, ethnic and linguistic groups, a great majority of respondents, 89%, selected "essential/critical" (41%) or "very important" (48%).

Challenges and barriers

"Also, there is a high turnover of service coordinators/case manager in the regional center system, causing families to often lose their case manager or change new managers. Many times, these managers are not knowledge of the regional center systems and services"

When asked to describe challenges and barriers that impacted implementation, respondents indicated that lack of knowledgeable staff, inconsistent ability of families to schedule and participate consistently, and COVID. Barriers included the difficulties families face in accessing and navigating the complex DDS system and services not being provided in their primary language.

Outcomes

"Our project has helped thousands of families with direct connection the Regional Center, both for Early start, Lanterman Act services, and additional generic resources for individuals with IDD."

When asked about the most significant outcome from their SAE grant project in terms of disparity reductions, most CBO grantees reported that there was increased engagement and knowledge of resources and services offered at regional centers and CBOs. Other significant outcomes mentioned by respondents included increased self-advocacy and knowledge of service recipients, increased capacity of CBO's, strengthened relationships and supports between families and regional centers, having more leaders and staff that represented the service recipient population, and increased purchase of service.

"We were able to increase equity by educating, empowering and mentoring the Asian families in accessing services from the regional center. With more understanding of the services they are entitled to, families learned to ask their service coordinators or case managers about those services that they did not know about before. There were also more families who applied for regional center intake. Also, by reducing staff turnover, we were able to keep our bilingual staff to continue to support our Asian clients. Without these staff, there would be no programs for clients with language and cultural needs."

Recommendations for improvements

CBO grantees made many recommendations for quality improvements for DDS. The recommendations that were mentioned the most were to decrease regional center gatekeeping and increase communication and collaboration across organizations. Other recommendations included making changes to the grant and reporting system, improving staff and training, improving language interpretation and translation access, changing funding, and simplifying the system.

"Make regional centers' participation in and collaboration with funded projects more 'real' and less political. Right now, all projects are supposed to be 'approved' by the regional centers in whose catchment areas they operate. This creates a conflict of interests and breeds favoritism. There is simply no way that a regional center can learn in depth about all the programs in their catchment area, and be supportive of them all. Moreover, the regional centers compete for the same pool of funding as the CBOs, yet they are asked to approve projects submitted by their competitors. This is not a good system and potentially may lead to discrimination, especially against smaller CBOs, of the kind our program supports."

Data Brief: Community Based Organizations (CBOs) Survey

Number of Respondents – (n=34)

Table 1. Current role of CBO grantee staff (n=34)

Role	Percentage
Director or Founder	38%
Program Director or Manager	35%
Academic	9%
Vice President	6%
Program Staff	3%
Other	9%

Table 2. Number of years in this role/position (n=34)

Years	Percentage
1 – 2 years	21%
3 – 5 years	33%
6 – 10 years	27%
11+ years	18%

Figure 1. Self-reported number of years in current role/position from CBOs
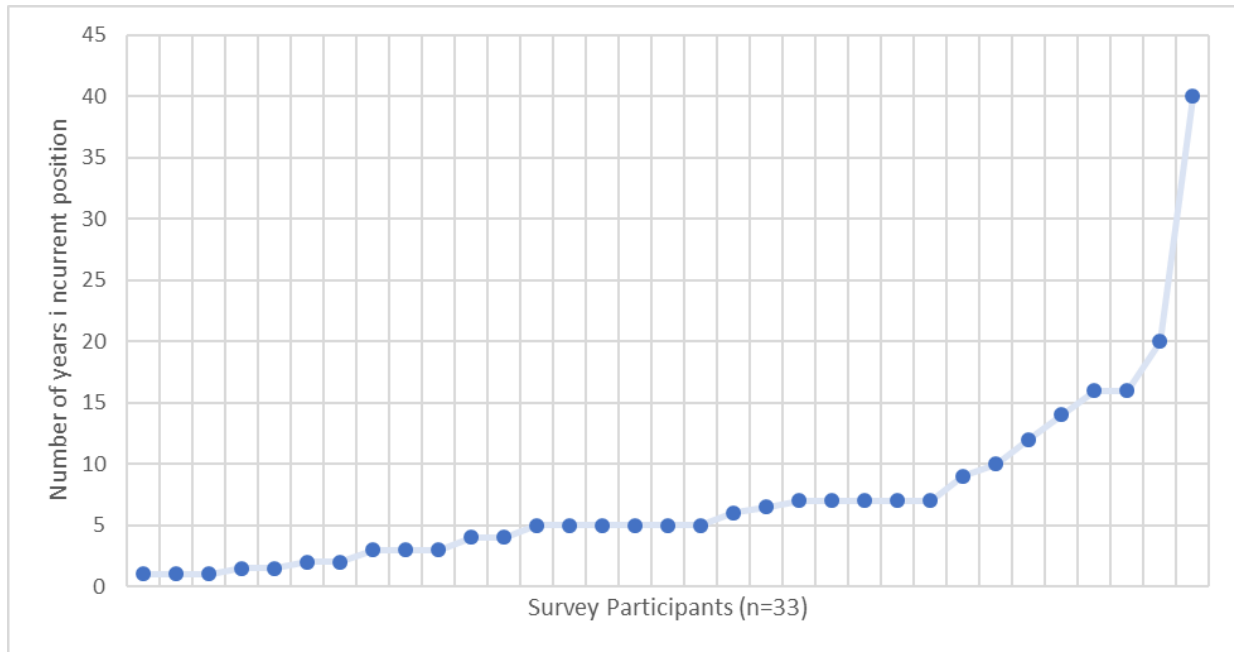
Table 3. CBO grantees' region (n=34)

Region	Percentage
Bay Area	41%
Southern California	32%
Los Angeles	18%
Central California	6%
Northern California	3%

Table 4. CBO grantees with multiple SAE projects (n=34)

Multiple SAE Projects	Percentage
Yes	24%
No	76%

Table 5. CBO grantees' number of additional projects (n=7)

Number of Additional Projects	Frequency
1 additional project	2
2 additional projects	2
3 or more additional projects	3

Table 6. CBO grantees' population focus for SAE project(s) (Represent multiple responses)

Population	Percentage
Hispanic/Latinx	59%
Black/African American	35%
Multiple marginalized groups or non-English speakers	15%
Native/Indigenous	12%
Vietnamese	15%
Chinese/Cantonese	12%
Filipino	12%
Korean	9%
Hmong	6%
Indian	3%
General South Asian	3%
General Asian	9%
Arab	3%
Farsi	3%
Mam	3%

Figure 2. Self-report population focus from CBO SAE grantee
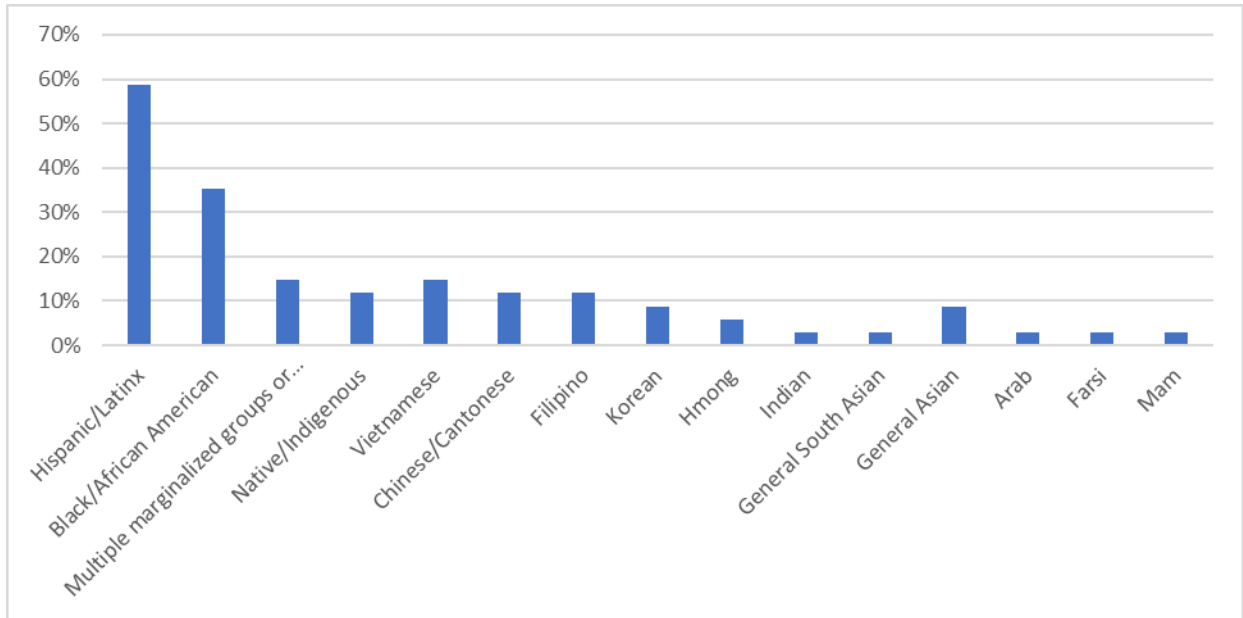
Table 7. CBO grantees' years of funding received for SAE project(s) (n=34)

Years of Funding	Percentage
1 – 2 years	41%
3 – 5 years	53%
6 – 10 years	6%

Figure 3: Self-report number of years of funding receiving for SAE projects
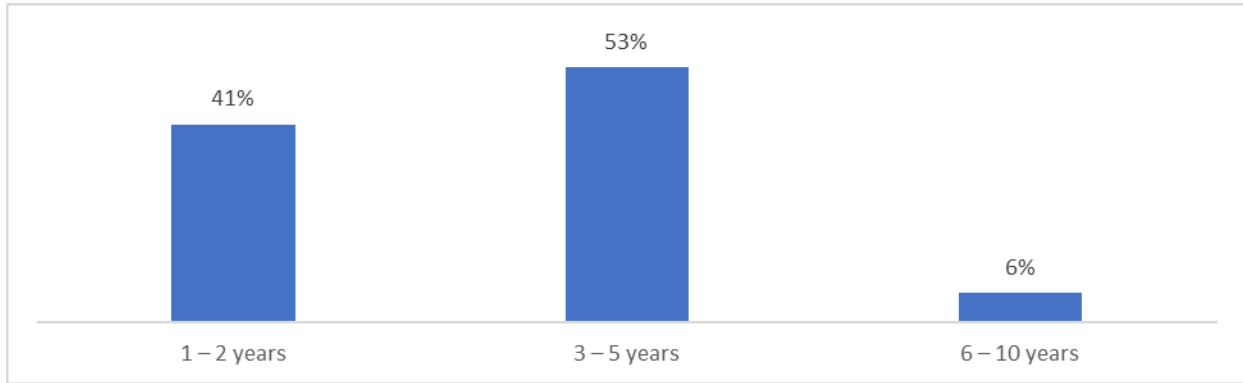
Table 8. CBO grantees' cycle(s) funded (n=34) (Represent multiple responses)

Cycles	Percentage
FY 18/19	59%
FY 19/20	76%
FY 20/21	76%
FY 21/22	82%

Survey Questions

Table 9. CBO grantees' reasons for submitting a proposal to DDS for the Service Access and Equity (SAE) program (n=20)

Coding Structure	Frequency	Illustrative Quotes
To improve equity and accessibility of supports and services	9	"Over the last year (name or information withheld for anonymity) has been working towards developing authentic partnerships with our target populations in order to create systems that meet their needs. Our intent is to center families that are most impacted and address systemic barriers to services." "The disparity for African American/Black Families is beyond what the numbers show. There is a disparity and injustice not only to families who are clients of the RC services but there is a lack of access to the information to even gain access into this system of care. The system seems to put this huge focus on linguistics as if that is the only disparity that exist."
To focus on underserved communities that are unaware of or not receiving services	8	"We applied for this program because statistics show that the Asian disability population has already been underserved with low POS utilization compared to its white counterparts due to cultural and language barriers. Another reason is that many families actually are unaware of the regional centers and the services they provide. Therefore, we feel that it is important for us as an organization whose target population is Asian to outreach to the Asian population to educate and empower the families to access services that can help their children."

Table 9 (continued). CBO grantees' reasons for submitting a proposal to DDS for the Service Access and Equity (SAE) program (n=20)

Coding Structure	Frequency	Illustrative Quotes
To obtain extra funding and resources to continue serving underserved populations	3	"(Name or information withheld for anonymity) decided to submit a proposal because in all of the work we do with traditional services, we found that most of our clients were from less fortunate socio-economic backgrounds. We struggle as an organization many times attempting to get help for clients with anything from food, furniture and services. We have and will always resolve to using any additional resources we have and sometimes not to help the individuals we are serving. We observe budgets being expanded, yet taking extended times to reach the consumers and their amazing staff. We decided this was an excellent way to help be a part of the solution for underserved communities and expand the work we currently provide." "This is the second time we received this grant. The first time was number of project withheld for anonymity for two years. (Name or information withheld for anonymity) has served (Name or information withheld for anonymity) clients' catchment area for more than 40 years. (Name of organization withheld for anonymity) has a history of providing culturally-competent services to groups traditionally underserved such as cultural and racial minority groups, low-income families, and those who have limited English proficiency or disabilities themselves. We have seen and lived the disparities in services among the Hispanic and Vietnamese Communities. For this reason, we applied to this grant."

Table 10. CBO grantees' responses on whether the SAE project was expanding capacity or new work. (n=20)

Coding Structure	Frequency	Illustrative Quotes
Expanding capacity	11	"(Name or information withheld for anonymity) allowed our FRC to expand its support of our target population."
Creating new work	3	"The (name or information withheld for anonymity) project is new work under a united umbrella. Our goal and objective is to unit the efforts of Parents and Self-Advocates and empower them to address the barriers and roadblocks that families experience in trying to navigate the complex systems of support. We decided to submit a proposal because the Latino community within the ID/DD community in California has mostly been voiceless and as it is well documented the one receiving the least amount of services."
Both	6	"Project both expands capacity and is new work."

Table 11. CBO grantees' responses as to how their project was designed to reduce disparities at the following levels:

Coding Structure	Frequency	Illustrative Quotes
Individual level (n=32)		
By providing training and education to individuals in how to navigate the system and receive services.	18	"The participant is educated on navigating (name or information withheld for anonymity) from the perspective of an independent facilitator. This is increasing their knowledge for personal development and reduces disparities that they experience navigating the system." "Services provided by the CBOs reduce disparities in access (unmeasured by the POS measure used by the DDS) to social-recreational and other community-based services at the individual level. For example, if a CBO in our cohort provides adaptive swimming / skate-boarding / surfing / wilderness hiking programs, individuals are able to access these services in their community free of charge or for a very low, nominal fee. Regional Centers fund swimming instruction, however, there are very few vendors providing this service. CBOs increase access to hard-to-get services for individuals." "Increase the knowledge of information about the available services and ability to obtain the appropriate services to their children with I/DD."

Table 11 (continued). CBO grantees' responses as to how their project was designed to reduce disparities at the following levels:

Coding Structure	Frequency	Illustrative Quotes
Individual level (n=32)		
By providing services that address individuals' cultural and linguistic needs	4	"Working with indigenous communities came with the challenge of addressing disparities in the languages they understand. It is not just Spanish that they cannot communicate in but also the challenge of not being able to read or write and that their native tongue is verbal. We help families one on one to learn about what is available and give them space to express concerns."
By helping individuals to learn how to be self-advocates	3	"We have been assisting individuals mainly in the area of advocating for themselves and understanding their rights."
By increasing individual's skills	4	"The (name or information withheld for anonymity) project is designed to impact individuals directly by providing skill training and experience to six individuals from the BIPOC IDD community with up-to-date experience in 10 different fields of remote work, as well as education on self-advocacy skills, communication skills, and other technology skills." "We outreached targeting under-served Chinese/Vietnamese communities to promote RCEB & DD services. We provided brief screening for identified Chinese/Vietnamese clients to be referred for RCEB intake through different channels of contacts. We recruited, trained and ensured IDD internship placements for a cohort of foreign health professionals and immigrant workers."
Project as not designed to address disparities at this level/N/A	3	"It wasn't really designed to do this, but some personal testimonies indicated that we did make a difference for some at the personal level."

Table 11 (continued). CBO grantees' responses as to how their project was designed to reduce disparities at the following levels:

Coding Structure	Frequency	Illustrative Quotes
Family level (n=32)		
By providing training and education to families in how to navigate the system and receive services.	21	"Through training (name or information withheld for anonymity) with new skills and resources, families are impacted. (Name or information withheld for anonymity) can help families with systems navigation through the regional center. (Name or information withheld for anonymity) are also developing new social media and printed materials to assist families. (Name or information withheld for anonymity) are likelier to refer families to Regional Center and help them advocate and ask for services." "The participant is educated on navigating (name of project withheld for anonymity) from the perspective of an independent facilitator. This increases their knowledge for personal development and reduces disparities that they experience navigating the system, as they have the knowledge to successfully navigate. The cascade impact to the family and self-advocate is the improved quality of life from accessing services and supports." "Parent Navigators, parents themselves of individuals, are employed to be embedded in a general pediatrics clinic and directly, one-on-one help individuals and families access Regional Center services, both through initial application, and troubleshooting when more services are needed." "Parent leaders will work in the community to provide training on (name or information withheld for anonymity) services, and coaching/support groups where they will provide peer-to-peer support in navigating services, and refer families to (name of CBO withheld for anonymity) or (name or information withheld for anonymity) for additional support. Families referred to (name of CBO withheld for anonymity) will be supported by our Family Resource Specialists for any barriers to service navigation and by our social worker and case manager for additional short-term case management or clinical support. (Name or information withheld for anonymity)'s Family Resource Specialists and case managers also provide peer support since they are parents of children with disabilities and speak Spanish and Cantonese."

Coding Structure	Frequency	Illustrative Quotes
Family level (n=32)		
By providing services that address the cultural and linguistic needs of families	8	"(Name or information withheld for anonymity) facilitates private, 1-on-1 conversations between Regional Center staff and Hmong parents/caregivers to identify and address specific cultural and linguistic conditions that can improve care. At the family level, Regional Center staff learn how to work with Hmong families in ways that are more culturally and linguistically appropriate and effective."
By providing a safe space for community connections, relationships and conversations	5	"Allowing for a safe space for African American/Black families to share their frustrations. during 2020 delivering PPE to families and providing one on one counseling" "Our project was designed to normalize conversations of IDD in our communities and educate families through a sharing of stories. We also connected them with our local regional center and other resources and services"
By increasing the capacity and services of CBOs	2	"Parents and other family members experience disparities when there are no or limited services available - or approved - through the regional center system. By increasing capacity of the CBOs providing services in community settings, we decrease disparities in services at the family level because there are more programs that families are able to access, and the process does not require a long and potentially upsetting negotiation with the regional center."
By helping families to learn how to be self-advocates	3	"To educate and empower the special needs individual's family to advocate and access generic and regional center services to meet their child's needs. Provide emotional support and guidance for families to connect with service specialists and providers."
Project as not designed to address disparities at this level/N/A	1	"(Name or information withheld for anonymity) does not distinguish between individual and family services -- for example is IHSS a service for the family (in terms of financial support) or the individual consumer (in terms of getting individual assistance)."

Table 11 (continued). CBO grantees' responses as to how their project was designed to reduce disparities at the following levels:

Coding Structure	Frequency	Illustrative Quotes
Community level (n=30)		
By hosting events and create materials to educate and inform community about regional center services	7	"We have been able to continue to expand the knowledge of the Regional Center services to many amazing community partners through being vendors at resource fairs, presentations to community groups and our educational Wednesday Webinars."
By collaborate and communicate with regional centers and other agencies	6	"We connected with other organizations by creating live table talks on our social media platforms to discuss topics of concern. We also hosted story cloth circles available to community members."
By increasing awareness of disabilities and special needs	4	"To bring awareness of the special needs community to the community at large by hosting art exhibition, special needs talent showcase, resource and community fairs, special events and engaging them in local community events such as parades and festivals."
By providing opportunities for social networks, relationships, support systems	3	"Additionally, the parent-run CBOs serve as generators of social networks. People get to know each other through participating in the CBOs' programs, and this increases and strengthens their social support systems."
By working to build trust, strength, and self-advocacy skills	8	"Before this project, over ten groups serving the Spanish-speaking community were very divided. There was no cohesive advocacy or data collection system on the community's needs. There was distrust in inviting these groups to the table because of behavior interpreted as unprofessional. This has changed completely in the three years since implementing the community of practice." "CBOs providing services in under-resourced communities empower and strengthen their communities. There is an increased sense of self-efficacy when CBOs are able to create programs that otherwise either would not exist, or that would have been inaccessible, or very expensive."
Project as not designed to address disparities at this level/N/A	2	

Table 11 (continued). CBO grantees' responses as to how their project was designed to reduce disparities at the following levels:

Coding Structure	Frequency	Illustrative Quotes
Systems level (n=30)		
By providing and participating in training workshops and tasks force efforts	11	"At Systems level, we reduced disparity in IDD services to Asian-speaking consumers by providing training and consultation to participating IDD service providers on how to deliver culturally/ linguistic-ally relevant services to Asian/SEA IDD individuals and families. We made active contacts with vendorized IDD providers and held Advisory Council meetings (including IDD parent advocate, local IDD providers, (withheld for anonymity) representative, project manager, etc.) and workshops to identify IDD consumer needs, brainstorm strategies to improve our services, and implement strategies utilizing "Theory of Change" approach." "Actively participate in all the disparity reduction/access and equity workgroups from DDS, regional centers, and (Name or information withheld for anonymity) to resolve disparity concerns. "Many of the CBO leaders in our cohort have been engaged in the DDS taskforces and other state-level activities organized by the DDS, as well as other state agencies. Of course, we can't take credit for this. But we can take partial credit, very humbly, for supporting their work in a way that empowers them to make an enormous impact at the county and state level. Most of the CBOs in our cohort have stayed with us for almost the entire period this project has been funded. In total over 2,4 years we have supported over 30 CBO leaders. We also have supported emerging CBOs in an incubator model, helping the CBO leaders launch their organizations. Our project levels the playing field for parent-run CBOs in California, and this changes the DD and other human services systems."
By providing reports, results, data, and feedback from families	9	"Provide data, information on measurable outcomes and anecdotal reports of the family/individual experience as they navigate the regional center system in order to educate and inform system-level individuals."

Table 11 (continued). CBO grantees' responses as to how their project was designed to reduce disparities at the following levels:

Coding Structure	Frequency	Illustrative Quotes
Systems level (n=31)		
By partnering with other organizations	3	"Our outreach protocol is designed to be collaborative in nature. As it states within our name our objective is to integrate families from within the perspective of the community into the systems of support. We meet with RC Directors and Senior Staff on a monthly basis to discuss issues and areas of concerns as well as best practices. In addition, we collaborate and meet regularly with statewide organizations like (withheld for anonymity) and others."
Not applicable	7	

Table 12. CBO grantees' responses on whether they used culturally competent approaches to implement the grant specifically in supports, services, and project activities (n=31)

Coding Structure	Frequency
Yes	31

Table 13. CBO grantees' descriptions of culturally competent approaches used to implement the grant specifically in supports, services, and project activities (n=29)

Coding Structure	Frequency	Illustrative Quotes
Multicultural/ Multilingual staff and parents	12	"Our focus is on one cultural group. The leadership of the org is of that culture and has been trained to serve the culture better in different aspects." All of our staff members are parents or siblings related to I/DD children/people so we know how other parents think and need and how to provide supports, services and activities to our members."
Provided services in the language of the community or translation	8	"The migrant indigenous community serves indigenous language speaking communities. We have projects that are in Mixteco, and "Zapoteco."
Provided Trainings (regarding culture and bias)	6	"Yes, our project included cultural competency training, an organizational audit, community outreach training. The project was developed with the support of consultants who are experts in the area."

Table 13 (continued). CBO grantees' descriptions of culturally competent approaches used to implement the grant specifically in supports, services, and project activities (n=29)

Coding Structure	Frequency	Illustrative Quotes
Provided Cultural activities	6	"We also host coffee socials in Chinese to support our Chinese families. In some instances, our mentors accompanied our families to IEP or IPP meetings."
Used a Peer to peer model	2	"We are the only CBO in our catchment area that is using a peer-to-peer model to connect with families of children with disabilities and special healthcare needs and working to build authentic partnerships with our target communities to change systems that are not working for them. As our authentic partners, parent leaders are involved in all aspects of the project, including the identification of what they would like to see in this next phase of the project. They will continue being central to the development and implementation of this project and will receive continued mentorship, support, and access to professional development and leadership opportunities. Parent leaders will be compensated for their time, receive professional development and mentorship, and receive a certification of completion once they complete the training portion of the project."
Consulted cultural members and experts	2	"We drew on former focus groups with Spanish-speaking parents to develop procedures; we also drew on related research studies."

Table 14. CBO grantees' responses on whether they used linguistically approaches to implement the grant specifically in supports, services, and project activities (n=31)

Coding Structure	Frequency
Yes	29
No answer	2

Table 15. CBO grantees' descriptions of linguistically approaches used to implement the grant specifically in supports, services, and project activities. (n=27)

Coding Structure	Frequency	Illustrative Quotes
Provided translation/ interpretation of materials forevents, and services	21	"We hired staff who spoke in various Asian languages including Vietnamese, Mandarin (Chinese), Cantonese (Chinese), and Burmese. We translated videos, and flyers into Asian-languages to promote services to Asian-speaking IDD population."
Bilingual and/or bicultural staff	11	"Our project staff speak fluent Cantonese, Vietnamese and Tagalog and communicate with participants in their native languages."
Utilized plain language	1	"While the project addresses the needs of BIPOC leaders who are all native English speakers, or highly acculturated if they are not, we use plain language and other approaches to develop our content in a linguistically competent way."

Table 16. CBO grantees' responses on whether they used a theory of change framework for their SAE grant project (n=27)

Coding Structure	Frequency
Yes	15
No	11
Don't know	1

Table 17. CBO grantees' descriptions of the theory of change that was used

Coding Structure	Frequency	Illustrative Quotes
Yes (n=9)		
Used pre and post measures	4	"We use pre- and post-surveys to measure knowledge state change in most of our activities. We also use Clifton Strength surveys, SMART survey, and National Core indicators (surveys, not interviews). Our intention was to run NCIs pre- and post-program even though we know that the instruments are not designed to measure change. We adapted our approach to use NCIs several times over the course of the program to gather cohort-level data. Our theory if change is that as our program helps increase capacity of CBOs to provide services, the improvements in access will be reflected in the NCI's community participation domain."

Table 17 (continued). CBO grantees' descriptions of the theory of change that was used

Coding Structure	Frequency	Illustrative Quotes
Yes (n=9)		
Based on individual and system advocacy	2	"Our theory of change program design is based on engaging our community and uniting our voice by empowering individuals to be part of the process and solution."
Used the Promotora model	1	"We utilize the Promotora model. and are firm on building trust with the community as they share their stories and their concerns. We are flexible on their work schedules and are patient in the learning curve they have."
Emergent Theory	1	"Emergent Strategy - change is a continuous process with an open, unpredictable end, in which we must adapt to constantly - be like water."
Social Learning Theory	1	"(Name or information withheld for anonymity) is based on principles of Social Learning Theory, specifically learning through one's social environment and through practice. The aim is to provide Regional Center staff more live, interactive opportunities to practice their communication and other interactions directly with Hmong parents in a safe and nurturing environment (e.g., the facilitated conversation)."

Table 17a. CBO grantees' descriptions of why a theory of change was not used.

Coding Structure	Frequency	Illustrative Quotes
No (n=8)		
No official or specific theory was used	3	"Theory of change is something that is rather new to us as an organization."
Unaware of theory of change	2	"We did not use a specific theory, but did use our model of providing the equal access to information in the family's home language whenever possible."
Didn't understand the question	1	"We don't know because we don't understand the question."
No specific reason	1	"Not part of our development process. There is not a specific reason it was not used."
Focused on teaching/learning about what needed to be changed	1	"The particular project described here was less an attempt to induce "change" and more of an effort to both teach and to learn more accurately what needed changing."

Table 18. CBO grantees' responses on whether they used a logic model to demonstrate the correlation between advancing equity and disparities reduction within their grant project (n=31)

Response	Frequency
Yes	14
No	12
Don't know	5

Table 19. CBO grantees' description of the logic model that was used

Coding Structure	Frequency	Illustrative Quotes
Yes (n=12)		
Included a basic logic model based on problem/solution and cause/effect	5	"By identifying the root of the barrier, capturing the elements of the problem and offering a solution for all participating parties."
Based on feedback and/or collaboration	3	"We used a group process in developing our logic model, to bring key stakeholders together to clarify the underlying rationale for the program and the conditions under which success is most likely to be achieved. At our monthly Advisory Council Committee meetings, our group logic model helped us strengthen our program because everyone involved – program staff, participants, and other stakeholders – has a shared understanding of what the outcomes are, and the key activities and processes that need to occur for these outcomes to be achieved. Along the way, we did "check in" to see if things are going as planned or if adaptations need to be made. We analyzed our inputs, activities strategically (from outreach activities to methods of delivering training during the pandemic, and building job provider relationships, etc.). From our inputs and activities, we analyzed our outputs and outcomes on a bi-weekly basis internally as a (name or information withheld for anonymity) team with our contractors, then on a monthly basis at our Advisory Council meetings to see what assumptions were made and where we can improve."
Did not formally develop a logic model	2	"We did not officially develop a logic model, but intuitively we utilize the concept of a logic model. We were moving so fast in the 1st two years of the grant because of pandemic we just did the work because the needs were rapidly changing. However, for year 3 we have developed a project plan and yes a logic model."
Based on an ecological model	1	"Ecological model"
Based on DDS milestones	1	"Through the designs of the milestones with DDS."

Table 19 (continued). CBO grantees' description of why a logic model was not used

Coding Structure	Frequency	Illustrative Quotes
No (n=5)		
Wasn't requested or suggested	2	"We didn't use this model because it wasn't requested. Had it been required (or even suggested) we would have."
Did not understand the question	1	"We don't know because we don't understand the question."
No experts available on team to create a logic model	1	"We didn't develop a logic model--we don't have an expert on our team to create this with/for us."
Approach cannot be modeled on a linear level	1	"Our approach is too multi-dimensional and dynamic to be reflected in a linear logic model."

Table 20. CBO grantees' responses on whether they engaged persons with intellectual and developmental disabilities (IDD) and their families to evaluate supports and services provided by their SAE grant project

Response	Frequency	Illustrative Quotes
Yes (n=25)		
Through the use of feedback efforts	14	"We included surveys and conversation questions as way to gain feedback, evaluate progress, and identify priorities." We always try to obtain social validity measures."
Through collaboration and involvement of family members	11	"As mentioned above, we created a (name or information withheld for anonymity). Additionally individuals with IDD and family member are members of the (Name or information withheld for anonymity) Board of Directors. The majority of (name or information withheld for anonymity) team members are parents or family members of individuals with IDD." "In addition, our staff and participants include self-advocates."
No (n=2)		
No	2	

Table 21. CBO grantees' responses on what they have found to be the most significant challenges in implementing their SAE grant project (n=29)

Coding Structure	Frequency	Illustrative Quotes
Attrition and lack of knowledge of staff	15	"Also, there is a high turnover of service coordinators/case manager in the regional center system, causing families to often lose their case manager or change new managers. Many times, these managers are not knowledge of the regional center systems and services" "Among the most important components of anonymity)is the identification of differences (cultural clashes) between Hmong and mainstream culture that, if addressed, would improve specific services to and engagement of Hmong people. Too often when working with Regional Center staff, the staff have a difficult time in naming the specific way cultural and linguistic differences may affect services and care. Often, staff say "we just want to learn about Hmong culture" or other broad statements. Identifying specific cultural factors (e.g., how one introduces themselves to Hmong elders, and how to ensure more personal communication with Hmong parents) is an ongoing challenge that makes this work exciting."
Ability of families/clients to schedule and participate consistently	8	"Implementing the programs wasn't a problem; we continued with the same programs as the previous gran. The biggest challenge is keeping the families attending online programs." "While we were ambitious in achieving the goals we laid out for our community, we found out that we had to keep pulling back due to the challenges of lack of knowledge and resources families lacked when asking for support which caused us to fall behind."
COVID	4	"Some of the greatest challenges were due to the fact the project was up and running right when COVID-19 started so we had to shift many strategies and activities to support individuals during the time. The structure was incredibly impactful to help our individuals and families through the pandemic."

Table 21 (continued). CBO grantees' responses on what they have found to be the most significant challenges in implementing their SAE grant project (n=29)

Coding Structure	Frequency	Illustrative Quotes
Time	3	"Data collection is time-consuming, however we have now created a system that allows for gathering family input, surveys and consents."
It is difficult for families to navigate the system	3	"Lastly, families can learn information and try to advocate for their child(ren) based off what they now know, but systems are still making many barriers--families give up because although they know they are able to get various services, when they request them they don't get them--there are delays, denials, obstacles. Families have limited capacity to keep fighting when they get told no so many times."
Working with regional centers	3	"Collaborating with the Regional Center is a real challenge. We have little cooperation and collaboration from services coordinators, including the Multicultural specialist. Connecting with them to help a family solve a problem is a big challenge."
Families lack access and knowledge of technology	2	"Second, grassroots outreach is necessary to reach our target populations. A lot of them do not know how to use technology and the internet or do not have access to those devices"
Frequency of grant writing and reporting requirements	2	"Burden of annual competitive grant writing - Our targeted Cantonese, Vietnamese, Filipino adult consumers and families have been underserved for decades. It will take multi-year efforts to effectively reduce disparities. Projects that have proven track record should be funded multiple years rather than having to re-apply and compete for the funding each year. For example, all 21 Regional Centers just received multi-year funding for language access and cultural competency this year past, so did the (name or information withheld for anonymity) agencies in CA."
Feelings of uncertainty and skepticism from families	1	"When contacting individuals from the (name or information withheld for anonymity) low to no POS data list, many were leery initially. At the onset before our collaboration became stronger with the Regional Center, some service coordinators did not take well to contacting individuals on their caseload. This was due to the communication about the project was not distributed in the beginning as agreed upon. It was also prior to our quarterly workgroup meeting that started this year."

Table 22. CBO grantees' responses on whether their SAE grant project worked directly with persons with IDD and their family members from racially, ethnically, culturally and linguistically diverse backgrounds (n=31)

Coding Structure	Frequency
Yes	29
No	2

Table 23. CBO grantees' descriptions of the barriers encountered in working directly with persons with IDD and their family members from racially, ethnically, culturally and linguistically diverse backgrounds (n=27)

Coding Structure	Frequency	Illustrative Quotes
Services are not provided in the primary language or based on the families circumstances	13	"The barriers mostly are the services available for the families. They are not in their primary language and the providers aren't multicultural competent." "Spanish speaking families not accessing webinars - prefer Zoom meetings, some topics not as applicable to families of diverse financial backgrounds, various citizenship statuses."
Accessibility of transportation and technology	5	"We did not encounter much barrier in our work with our target population because our project staff are bilingual and bicultural. However, the barriers encountered by Cantonese, Vietnamese and Filipino families are multiple - language barrier, informational barrier, lack of bilingual/bicultural service providers, transportation barrier, technology barrier..."
Family member's time to participate in services	4	"The majority of participants are family members, but there is a small representation from Self-Advocates. The families are stretched and the nature of that is that there are competing priorities for their time to engage."

Table 24. CBO grantees' responses of the most significant outcome from their SAE grant project in terms of disparity reductions (n=29)

Coding Structure	Frequency	Illustrative Quotes
Increased engagement and knowledge of resources and services at regional centers and CBO's	16	"Our project has helped thousands of families with direct connection the Regional Center, both for Early start, Lanterman Act services, and additional generic resources for individuals with IDD (detailed data available upon request."
Increased self-advocacy, knowledge about disability, and confidence obtaining services	8	"Parents/caregivers have learned about their child's condition, what services/supports/treatments can help their child, and how to advocate for their child to access these services."
Increased capacity of CBO's and creation of new programs	4	"Increased capacity of the CBOs in our cohort to acquire funding to support and grow their critically needed, often life-saving programs (e.g. domestic violence prevention; adaptive swimming instruction; self-determination program support; competitive integrative employment support; among many others)"
Strengthened relationships and increased supports between families and regional centers	3	"The most significant outcome is creating an additional layer of support to serve as a liaison among individuals, families, community resources, and the regional center. We have been able to sustain these positions and have seen the incredible impact that it has on the individuals and families we support."
Leaders and staff represent service recipient population	2	"Systemically - now we have leaders representing the Latino community to participate in focus groups and other policy-making meetings. The Community of Practice comprises leaders with a better reputation and are seen as more professional."
Increased POS	2	Helping Cantonese, Vietnamese and Filipino adult consumers learn about and access regional center funded services that they did not know about or had not received, such as tailored-day service, supported employment, independent living skills training, adult day program, out-of-home respite, self-determination program... thus increasing their POS and reducing disparities.

Table 25. CBO grantees' responses of the data they collected to document disparities reductions resulting from their SAE grant project (n=30)

Coding Structure	Frequency	Illustrative Quotes
Data from surveys, pre/post-tests, evaluations	16	"We collected qualitative data - individual stories, workshop surveys, and satisfaction surveys. Provider feedback and engagement surveys."
POS/people served/attended/ participation/referrals	16	We are dependent on Regional Center POS data, and their data is always a lagging indicator. "Number of new generic and regional center services accessed" The number of referrals to school and Regional Centers" "Data primarily included attendance/participation numbers" "- Number of client who are regional center clients - Number of clients who have received intake and who have been accepted"
Social media interactions	6	"We were able to collect data from our social media postings about how many people our posts reached and how many interactions we were able to capture."
Not applicable	4	"Regrettably, we did not gather data to directly address this. For example, it was impossible to know exactly how many families were in need our program."
Data on barriers	3	"Types of barriers to accessing regional center services and community resources reported by Latinx individuals and families"
Demographics	3	"Disparity Target - Number of LatinX people served"
Program and event offerings	2	"workshops and trainings support groups"
Translations/interpretations	1	"Number of materials translated and interpretation services provided Types of the documents translated"

Table 26. CBO grantees' responses on whether they collected and analyzed data on project findings by each of the following: (n=29)

Coding Structure	Yes	No
Race	18	10
Ethnicity	20	6
Languages spoken	22	6
Geographic locale	7	17
Socioeconomic status	17	10
Other factors (including disability, age, staff experience)	12	8

Figure 4. CBO grantees responses to data collection and analyses efforts in the abovementioned categories
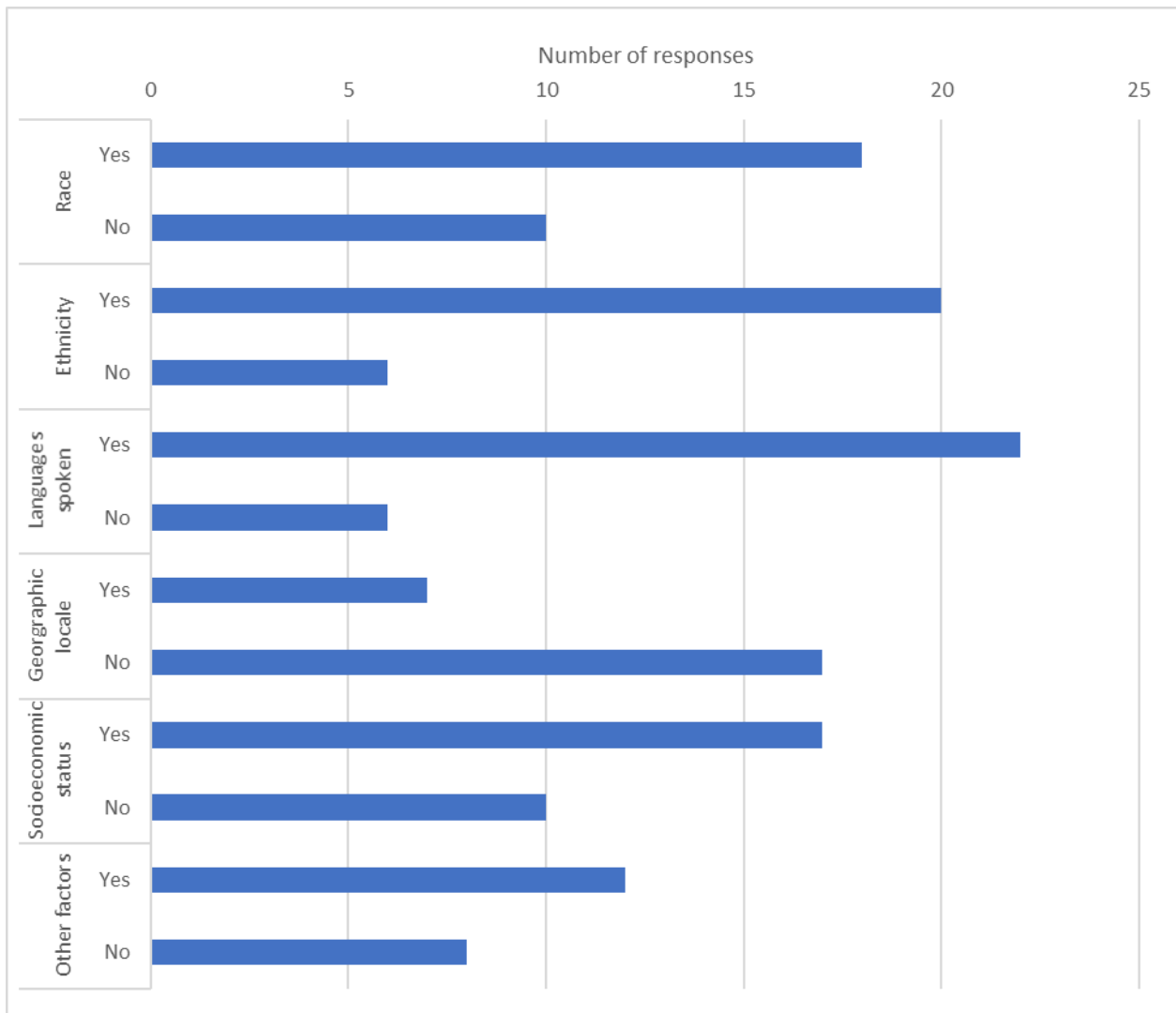
Table 27. CBO grantees' responses on their current capacity for collecting, analyzing and reporting on disparities data for the SAE grant project (n=30)

Coding Structure	Frequency
High capacity	6
Moderate capacity	17
Low capacity	6
No capacity	1

Table 28. CBO grantees' responses on whether the SAE grant project increased availability (n=27)

Coding Structure	Frequency	Illustrative Quotes
Yes	22	"The types of support. Mainly the connections to various resources." "The SAE grant enabled us to build capacity and increase our collaborative partners which in turn enabled us to provide better supports and services to our target population." "We increased availability of Asian-speaking IDD providers, and caretakers to serve the Asian-speaking IDD population." "Our bilingual, bicultural project staff made intensive one-on-one system navigation support available to monolingual adult consumers and their families members"
No	3	"SAE reduced the funding to less than half of the requested funding this year, so we had to reduce all the available programs to the half"
Don't know	2	

Table 29. CBO grantees' responses on whether the SAE grant project increased accessibility (n=30)

Coding Structure	Frequency	Illustrative Quotes
Yes	25	"We mentored to families to assist them in accessing more generic and regional center services. We provide language interpretation and translation for families with limited English ability for our seminars, parent meetings and coffee socials. We provide in-person services as well as virtual services for those who have more difficulty traveling to a location. Some of the families that we do not have language capacity to support, we refer them to agencies who can support them." "Our bilingual project staff have helped consumers and families access generic and regional center-funded services that they did not know about before." "Language access is always improving as we are helping outside agencies with families navigating the services. We are also available to the families for personal one on one appointments outside of their work schedules sometimes being open after 6pm and on weekends."
No	4	"Our grant's focus was on education/outreach to families, not on expanding vendored services." "The previous project wasn't set up to do this; our current one (we are in the middle) is intended to reach more people and hence increase capacity and accessibility."
Don't know	1	

Table 30. CBO grantees' responses on whether the SAE grant project increased acceptability (n=27)

Coding Structure	Frequency	Illustrative Quotes
Yes	21	"We provided (name or information withheld for anonymity) workshops to destigmatize cultural stigma and promote seeking help for families dealing with IDD family members. This helped increased acceptance to receive IDD training and providing support, as well as, asking for support." "Families were more open exploring services and options when they were working with a trusted person that they have developed a relationship in their preferred language." "Many ethnic minority clients are not utilizing their Purchase of Service due to lack of culturally and linguistically competent providers. Many of the (name or information withheld for anonymity) services have been parents and clients driven, so our services are developed to support the clients' person-centered needs. 95% of our staff and volunteers are culturally and linguistically competent. Therefore, our clients and families are very accepting of the services and supports that they are receiving from (name or information withheld for anonymity."
No	3	"Our grant's focus was on education/outreach to families, not on expanding vendored services. There has not been an opportunity to provide this input back to DDS or the RC"s in a clear and meaningful way."
Don't know	3	

Table 31. CBO grantees' responses on whether the SAE grant project increased quality (n=27)

Coding Structure	Frequency	Illustrative Quotes
Yes	19	"Resource material was carefully vetted to ensure the accuracy of complicated subjects." "The quality of our programs have improved as our programs are geared toward person-centered, and we have culturally and linguistically competent instructors who are knowledgeable in the area they are teaching. Our family support services are top quality as well because we invite experts in their topic to come and present to our families." "Improved quality of services with respect to being more culturally and linguistically appropriate is being self-reported by both staff and parents." "One of the hallmarks of our program is the extraordinary quality of the programs that the CBOs provide. Uniformly, the CBO leaders pour their hearts and souls into the programs they develop. This places them apart from programs that run under business models."
No	5	"Our grant's focus was on education/outreach to families, not on QI efforts for vendored services."
Don't know	3	

Table 32. CBO grantees' responses on whether the SAE grant project increased utilization (n=27)

Coding Structure	Frequency	Illustrative Quotes
Yes	23	"Although we serve mainly the Asian special needs population which has been increasing over the years, we have also increased the number of other ethnic groups such as the Hispanic population. We have more Hispanic clients than a few years before" "We have helped increase the utilization and purchase of services (POS) for Cantonese, Vietnamese and Filipino adults through our projects." "Self-reported information from parents suggests this service utilization is happening. We would love more direct measures of this. Currently, POS data for Hmong are only disaggregated for people who report speaking Hmong. Hmong as an ethnicity continues to NOT be separated from the larger Asian group. This is a big disadvantage in the evaluation of programs working to reduce disparities for the Hmong community."
No	0	
Don't know	4	

Table 33. CBO grantees' responses of strategies that were used to reach individuals and their families that are either unknown or not receiving services through the Regional Center (n=29)

Coding Structure	Frequency	Illustrative Quotes
Outreach events, seminars, fairs	14	"We work with partners and their promotoras to do outreach to schools and other organizations in an area where the underserved community resides. (Name or information withheld for anonymity) never referred any new family for additional support"
Media and social media and workshops	7	"We understood that social media and newspapers were great tools to connect to the community. We sent public service announcements and posted information about our services in Vietnamese and Chinese newspapers like Mo Magazine, Sing Tao Daily. These are the most popular newspapers for Vietnamese and Chinese in the East Bay. Besides community outreach, we also provided workshops in Chinese and Vietnamese to help parents get more information on how to support their IDD children."
Partnerships and collaborations	5	"We went through agencies other than regional center (or in addition to) to find families, e.g., other state agencies, contacts through Indian tribes, involving community members and local cultural or resource centers to reach out." (Name or information withheld for anonymity) using the train-the-trainer model, we increased our capacity from one organization trying to serve these families to 26 organizations reaching these families with the same quality information."
Word of mouth	4	"We placed Parent Navigators in a place highly accessed and trusted by families - their pediatrician's office. We hired navigators who were from the community served, who were approachable, kind, and able to say "I have been there and this helped" which made many more families comfortable with the process."

Table 33 (continued). CBO grantees' responses of strategies that were used to reach individuals and their families that are either unknown or not receiving services through the Regional Center (n=29)

Coding Structure	Frequency	Illustrative Quotes
Personalized outreach	3	"Families that live in our counties are part of isolated communities, some out of city limits. In our organization we take the time to do outreach in their places of work at the beginning of their shifts. We do Pan y Cafe con el campesino and show up at a farm at 5am to give them coffee and talk with them about our work."
Training and education	3	"By developing a knowledgeable group of participants there is a cascade impact in the community to engage individuals who are not receiving services."
Providing translations and interpreters	2	"We also provided linguistic support with families to refer them over to our regional center."
Proxy for connection	2	"We also connect the people directly to the people in charge in RC."
Project not designed to use strategies to reach individuals and their families that are either unknown or not receiving services through the Regional Center /N/A	5	"We have not been able to directly outreach to this population because RC is not able to provide us contact info for families that have $0 POS. We have asked that they consider contacting these families directly and informing them about the educational opportunities to learn about services/supports--but due to limited staff/time, this has not happened. We have a large database of families that have expressed interest in our events that we outreach to by email and now text also to inform them about educational events, and we also send our information out to various organizations that also serve this population so that families will hear about these efforts in multiple ways. In our experience (based on feedback from families), the families that have open RC cases w/ $0 POS would be best invited by a personalized phone call--because they may not have email, they may not read their emails, they may not understand what the event is without being provided an explanation, etc. But in order to do this, the RC would need to have staff to support such an effort. And then there should be tracking of the data--how many families answered, what was their response, were they encouraged to hear more about what services and supports they could use, did this lead to them accessing more support, etc."

Table 34. CBO grantees' responses of how the strategies used resulted in new individuals and families from diverse racial, ethnic and linguistic backgrounds accessing services (n=29)

Coding Structure	Frequency	Illustrative Quotes
Accessing services/resources and becoming new clients	11	"The new strategies help to increase the number of Hispanic and Vietnamese new cases. We were able to support and provide info to more families in person until the pandemic came, then the number freezer, and we only were able to access few families for a long time"
Increased trust, confidence, and connection	8	"By finding the individual, building a relationship and trust, informing and empowering and walk hand in hand with them through the systems of support."
Increased awareness, knowledge, and education about services	6	"…individuals and families receiving services from the CBOs learn about regional center services and are able to talk to their peers about their experiences"
Unable to track	1	"We are not able to track if our educational/outreach efforts have led to increased RC service access due to privacy regulations--we cannot share information about attendees w/ the RC and get data on how they are or are not accessing services."
Project not designed to use strategies to reach individuals and their families that are either unknown or not receiving services through the Regional Center /N/A	3	

Table 35. CBO grantees' responses of how important the grant program is to their organization's efforts to decrease disparities among persons with IDD across racial, ethnic and linguistic groups (n=27)

Coding Structure	Frequency
Essential/critical	11
Very important	13
Somewhat important	0
Important	2
Not too important	0
Not at all important	0
Not applicable	1

Figure 5. CBO grantees' responses to the importance of the SAE grant program to their organization's efforts to decrease disparities among persons with IDD across racial, ethnic and linguistic groups
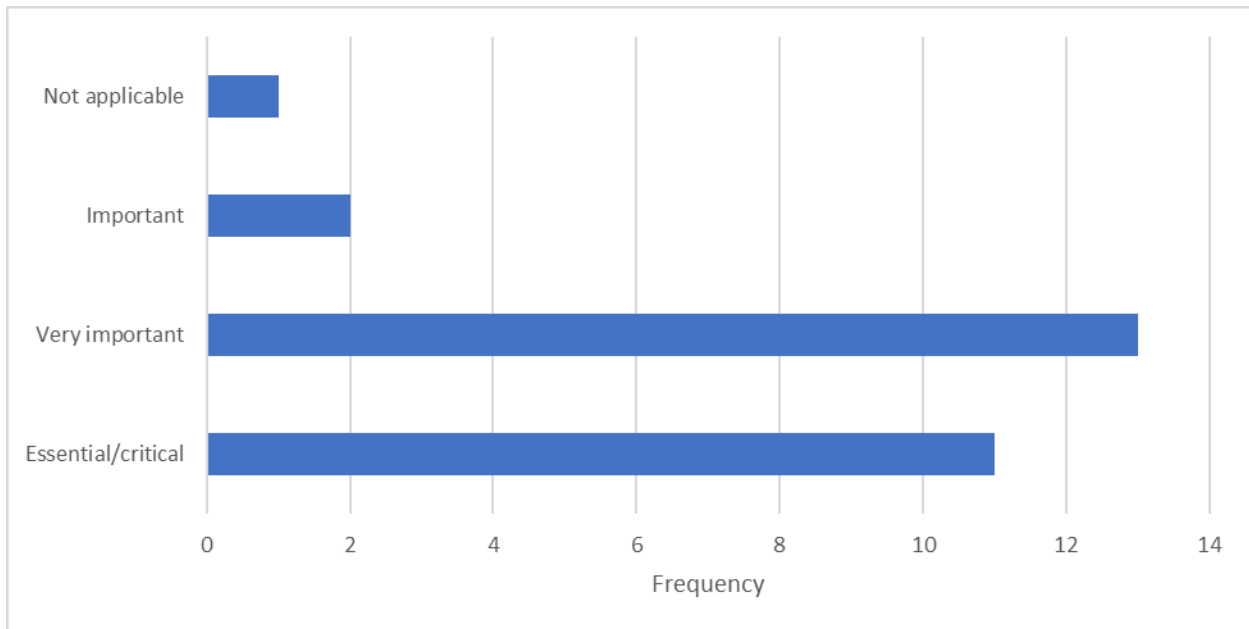
Note: These questions presented from tables 36 - 40, while intended and presented during the CBO listening sessions, were also presented as part of the survey in anticipation that some respondents may not participate in the listening session.

Table 36. CBO grantees' descriptions of root causes or factors that contribute to disparities in California's system for persons with intellectual and developmental disabilities (IDD) and their family members from racially, ethnically, culturally and linguistically diverse backgrounds (n=29)

Coding Structure	Frequency	Illustrative Quotes
Lack of cultural/linguistic competence through providers, services	14	"Lack of linguistically and culturally competent staff/caregivers or service providers to support the diverse IDD community so even if the clients have a POS, they can't utilize it."
System is inadequate, biased, too complex, and difficult to access	17	"The system is to complex and overwhelming to access and navigate. There is entrenched issues and problems that discriminate especially towards Latino families. Lack of uniformed process and accountability are contributing factors to many disparities. The darker your skin tone is and the stronger your accent the higher the issues and challenges." "Regional centers have become too complex to access and are compliance based. The cultural of NO prevails. The system is intimidating and, in many cases, families are retaliated against if they question their services."
Lack of information, knowledge, education, time	11	"Lack of information and understanding of how the regional center can support the individual and family."
Staff shortages	5	"Service coordinators should have more training to inform families. There are not enough multicultural providers available, there are long waiting for services, and a large number of cases are assigned to a service coordinator. Websites aren't easy to translate, and the important information is hidden, among other issues."

Table 36 (continued). CBO grantees' descriptions of root causes or factors that contribute to disparities in California's system for persons with intellectual and developmental disabilities (IDD) and their family members from racially, ethnically, culturally and linguistically diverse backgrounds (n=29)

Coding Structure	Frequency	Illustrative Quotes
Cultural stigma and attitudes	4	"The stigma surrounding disability in the Asian community. Some families do not seek regional center services before they do not want to be a RC client worrying that it may put a negative label on their children."
Funding requirements	2	"Dollars are focused on organizing, reporting, analyzing, workgroups and we are late to the party with the real issues of getting dollars and services to individuals/staff."
Immigration/ documentation concerns	1	"Receiving respite care is a huge barrier for immigrant families - especially undocumented families - because they cannot identify documented people to provide service."
Not applicable	1	

Table 37. CBO grantees' responses to successes achieved by their SAE project (n=28)

Coding Structure	Frequency	Illustrative Quotes
Increased education, awareness, outreach	12	"Increased understanding of regional center services individuals with IDD and their families."
Increased communication, collaboration	11	"Connecting with local organizations and organizations that are focused on the Hmong community that share a similar vision."
More services and resources provided/utilized	8	"Developed 5 new programs (2 high needs & 3 SDP ready) with total enrollment of over 30 students."
Higher participation/more clients	8	"Was able to reach and support over 500 families through our outreach events, coffee socials, parent support meetings and seminars and 1:1 mentorship."
Increased confidence and ability to advocate	8	"Parents report having a better understanding of their children's diagnoses and what services/supports are available and how to access these services."

Table 37 (continued). CBO grantees' responses to successes achieved by their SAE project (n=28)

Coding Structure	Frequency	Illustrative Quotes
Increased cultural and linguistic competence	5	"We increased workforce sector to provide culturally competent and linguistically diverse DSP, fast-track respite, and basic behavioral workers to serve the IDD populations primarily those who are Asian-speakers. We broke down cultural barriers to seeking appropriate IDD services and referred them to (name or information withheld for anonymity) for IDD service delivery. We increased availability of IDD services in various Asian-languages to promote and outreach to targeted neighborhoods."
Leadership Opportunities	5	"Getting our most vulnerable parents paid leadership opportunities."
Increased accessibility	4	"Helped shape and change RC culture to improve access of services to families."
Staffing improvements	4	"Increased capacity in the northern part of our county by adding resource coordinators."
Increased satisfaction	2	"Parents and children with I/DD are happier since they can meet and share their knowledge and feelings to each other."
Changes within organization and/or system	2	"2) Created a unified, engaged, empowered and branded presence in advocating for the Latino ID/DD community in California. 3) Helped shape policy and procedures to improve on the process to access of services and collaborated in Introducing legislation to change and revamp the (un)Fair Hearing Process."

Table 38. CBO grantees' responses to barriers encountered in implementation of their SAE project (n=28)

Coding Structure	Frequency	Illustrative Quotes
Hiring/staffing/training	8	"Recruiting and training multi-cultural staff to the point that they can effectively help families."
Challenges working with regional center	7	"1) RC staff in many cases resents the advocacy efforts and misconstrues them as adversarial in nature. Resistant to change. 2)RC changes the narrative and definition of directives policies and procedures as it best benefits them. In many cases it is a mindset of us against them. Very territorial."
COVID	5	"COVID-19 pandemic and the hardships and losses it brought about."
Technology	5	"Technology barrier -especially during the COVID-19 pandemic when we could not gather in-person, many participants do not know how to use video conferencing platforms such as Zoom."

Table 38 (continued). CBO grantees' responses to barriers encountered in implementation of their SAE project (n=27)

Coding Structure	Frequency	Illustrative Quotes
Reporting system and project demands	5	"It is difficult to gather detailed metrics and demographics because of the either the family's reluctance or due to the barriers with the way that data is compiled on the regional center end. Refining RC reporting systems in order to analyze data that can be used to more directly target individuals and families that are underutilizing services. Providers would then have the ability to specifically target and engage with those individuals to offer more services and supports."
Language and cultural barriers	4	"1) Continued stigma surrounding disabilities in the Asian culture and families worry about their child being labeled as disabled. 2) Lack of programs to support families with language and cultural needs."
Family concerns	4	"Receiving feedback in the way that works best for families. We started with surveys and learned about the difficulty with families responding and building trust. Informal conversations asking for targeted feedback worked much better."
Lack of community trust	3	"Building trust with the community takes time, 2-year grants are not long enough."
Accessibility	3	"Transportation barrier - Many aging caregivers do not drive."
Lack of information	2	"Declination of services leaving individuals in lower socio-economic situations stunned without knowledge of process to advocate."
Challenges within organization/ system	2	"Internal organizational challenges with our vision to center margins."
Funding restrictions	2	"Certain funding restrictions won't allow us to connect with families culturally."
Lack of guidance or uniform process	2	"A uniform process when helping families between transition of assistance, for example from early start to district services, or especially if families travel together while the parents work, that there is not easy way to transfer a family from one regional center to another."
Lack of participants or utilization	1	"Lack of participants."
Complex and time-consuming system for families	1	"The intake process is complicated and takes a long time. The application is long and complicated so families are hesitant in applying."

Table 38 (continued) CBO grantees' responses to barriers encountered in implementation of their SAE project (n=27)

Coding Structure	Frequency	Illustrative Quotes
Systemic racism and/or biases	1	"Structural racism in all areas of life; structural violence; constant struggle to overcome injustice and inequities; poverty;"
Low or noncompliance from families	1	"1. Still cannot get all members to be active 2. Some parents want to attend the training through Zoom and some parents want to attend the training through in-persons. As a result, we cannot get all of parents who want to learn from a training attend the training at the same time."

Table 39. CBO grantees' description of effectiveness of their SAE grant project in increasing equity/decreasing disparities (n=30)

Coding Structure	Frequency	Illustrative Quotes
Effectively increasing equity	21	"We were able to increase equity by educating, empowering and mentoring the Asian families in accessing services from the regional center. With more understanding of the services they are entitled to, families learned to ask their service coordinators or case managers about those services that they did not know about before. There were also more families who applied for regional center intake. Also, by reducing staff turnover, we were able to keep our bilingual staff to continue to support our Asian clients. Without these staff, there would be no programs for clients with language and cultural needs."
Effectively decreasing disparities	9	"The model decreased disparities by being able to provide support individual's in the language they prefer. The model decreased disparities by creating a link and liaison between families and providers. It helped individuals and families access the services that they need."

Table 40. CBO grantees' recommendations for quality improvement for DDS (n=28)

Coding Structure	Frequency	Illustrative Quotes
Regional center gatekeeping	9	"Make regional centers' participation in and collaboration with funded projects more 'real' and less political. Right now, all projects are supposed to be 'approved' by the regional centers in whose catchment areas they operate. This creates a conflict of interests and breeds favoritism. There is simply no way that a regional center can learn in depth about all the programs in their catchment area, and be supportive of them all. Moreover, the regional centers compete for the same pool of funding as the CBOs, yet they are asked to approve projects submitted by their competitors. This is not a good system and potentially may lead to discrimination, especially against smaller CBOs, of the kind our program supports."
More communication and collaboration across organizations	6	"Consider convening (virtually) organizations that are working w/ the same populations for more collaboration, sharing best practices/what's working and what's not, problem solving. While the all-CBO meetings are informative, there is not time for discussion or collaboration. Consider convening smaller meetings where CBO's can share barriers/successes in working w/ their corresponding RC's and provide this feedback to DDS so that DDS can better understand where the breakdowns or roadblocks are occurring and we can work together to address these. I.e., we can continue training families about what programs/supports are available, but if the families still face discrimination, are dismissed, are discouraged, etc. when they approach their RC requesting help, then we will continue to see lack of change in POS data."
Longer grant periods	5	"Fund projects for longer than two years. It really takes time and sustained funding to see the needle move on disparities."
Improve staff and training	4	"Train the service coordinators or case managers appropriately with the correct information so that they do not provide misinformation to the families. Many families have claimed that their case manager/service coordinator either doesn't know about certain services or they are providing the wrong information since they have learned the correct information from us."

Table 40 (continued). CBO grantees' recommendations for quality improvement for DDS (n=28)

Coding Structure	Frequency	Illustrative Quotes
Changes to grants and reporting system	4	"The application and reporting can be a large barrier to smaller organizations participating. There could be an opportunity to expand by providing a smaller funding opportunity that is aimed at smaller organizations. The application and reporting can be simpler so the organizations would have the capacity to participate. This would increase access and equity for this grant program."
Better language interpretation/ translation access	3	"Uniform websites and information that families and individuals can access anywhere and their primary language."
Increased standards and expectations for services	3	"Create standards and accountability across the board. Regional centers have little regard for the experience a family endures while trying to access services. Denial by delay is a thing because regional centers know no one will hold them accountable."
More funding	3	"I constantly hear that intake staff are overwhelmed... I would like to see funds distributed to increase intake staff, and increase the quality/decrease turnover/increase training of service coordinators."
Uniformity and standardization	3	"Also, a uniform way for coordinators to process families in the system. Our agency is willing to help but it is hard when we have to wait for approval for a form to be in Spanish. Then we lose families in the waiting period."
Less complex system	2	"I would suggest a system access overhaul, starting with how to find the appropriate Regional Center (there needs to be transparency about the health district aspect!), and there needs to be an easier way for families to apply for services. A universal application would be a start, it is so challenging to have each Regional Center have a different application process."
Changes to funding	2	"Only fund projects that fit exactly into the agency report-format, or fund original projects and require them to produce a meaningful, narrative report."
Improved accessibility of services and efforts	2	"I also wish that Early Intervention could be more prevention and center-based, sot that there does not have to be such detailed "proof" of a delay, but rather, if a family has any concern they can access some degree of services (more along the lines of universal preschool)."

Table 40 (continued). CBO grantees' recommendations for quality improvement for DDS (n=28)

Coding Structure	Frequency	Illustrative Quotes
Focus on root problems of disparities	1	"To continue to focus on the root problems of disparities. We have managed to make a major improvement but these efforts are still at the root growing level and need more time."
Implement ideas from projects in Regional Centers	1	"I am proud of the efficacy of our (name or information withheld for anonymity) program and would recommend that it be replicated not just in Family Resources Centers (which are already part of the regional center in some ways, which can be problematic for families who don't trust the system for the many reasons listed above), but in places families access regularly: doctor's offices, WIC offices, faith-based organizations, grocery stores, etc."
Providing mentorship	1	"Mentor to help newer programs"

Appendix I
Triangulation of the Qualitative Data

Triangulation of the Qualitative Data

Introduction

Triangulation is defined as combining multiple methods to study the same phenomenon (Lambert & Loiselle, 2008). For this project, data from interviews, listening sessions, and the qualitative responses to a survey were combined. While these data were collected independently, it was anticipated that their combination would generate complementary views. A recent literature review revealed the following rationales for triangulating data:

(1) overcoming unanticipated challenges - for example to analyze data from participants who were willing to participate in focus groups and those who were unwilling/unable to do so and had to participate in individual interviews (Triangulation, D. S., 2014);
(2) providing multi-faceted understanding – where the data completeness and/or confirmation is viewed by considering the findings across the various sources of data (Briller, Meert, Schim, Thurston, & Kabel, 2008); and
(3) supporting parallel use – so that data from one group (e.g., findings from interviewees) does not influence the findings from the other group(s) (e.g., findings from survey respondents) (Lambert & Loiselle, 2008).

For these and other reasons, triangulation can increase the validity of research results (Farmer, Robinson, Elliott, & Eyles, 2006).

Sample

Data from the Regional Center directors (RCs), Service Access and Equity (SAE) project managers, cultural specialists of the RCs, CBO staff, Department of Disability Services (DDS) staff, and family members of persons with intellectual and developmental disabilities were included in the triangulation methods. The number of responses for each of the seven sources is presented below.

Respondents	Data Source	# of Respondents
Regional Center (RC) directors	Interviews	18
Service Access and Equity (SAE) project managers	Interviews	16
Cultural specialists	Listening session facilitated via Thought Exchange™	9
Community Based Organization (CBO) staff	Listening session facilitated via Thought Exchange™	14
Community Based Organization (CBO) staff	Survey	34

Respondents	Data Source	# of Respondents
Department of Developmental Services (DDS) staff interviews (n=6)	Interviews	6
Family members of persons with intellectual and developmental disabilities	Listening session facilitated via Zoom™ and Thought Exchange™	70*

* Please note that 32 of the participants were SAE grant recipients. Their responses are the only ones included in this summary.

Methodology

Two triangulation methods as proposed by Briller et al. were used – methodological triangulation using multiple data collection strategies and data triangulation using information from different respondent types (Briller et al., 2008). There were three data collection strategies including interviews, listening sessions conducted through Zoom™ or ThoughtExchange™, and a survey of CBO staff. The respondent types were: Regional Center Directors, Service Access and Equity (SAE) project managers, cultural specialists of the Regional Centers, CBO staff, Department of Disability Services (DDS) staff, and family members of persons with intellectual and developmental disabilities.

To increase readability in the triangulation results section, family members of persons with intellectual and developmental disabilities (IDD) are referred to as "family members," DDS staff members are from the funding agency and are referred to as "DDS staff," and the other four (4) respondent groups: RC directors, SAE project managers, CBO staff, and Cultural Specialists are referred to as "SAE personnel."

Findings

Where it was feasible and statistically sound (such as when there were more than ten respondents), a mixed methods approach was used in presenting the findings of the qualitative (comment-based) data. That is, where respondent numbers were large enough and it was appropriate to do so, quantitative (numbers-based) analyses were conducted. Unless specified, percentages are based on the number of respondents who gave an indicated response compared to the total number of participants in the indicated data collection source.

The triangulation process revealed four themes:
1. There is a great need for racially, ethnically, culturally, and linguistically competent services, supports, and providers to address disparities and strategies for measuring these components;
2. SAE grantees have already initiated efforts in addressing some disparities, but more is needed;
3. There is a need to build capacity in SAE funded organizations, RCs, and CBOs overall so that caseloads can be decreased and staff are well trained;
4. Services and supports should be designed and allocated through the lens of family members as empowered advocates.

Theme 1: There is a great need for racially, ethnically, culturally, and linguistically competent services, supports, and providers to address disparities and strategies for measuring these components:

<u>**On theme 1, triangulated data revealed**</u> that there was agreement by families, and SAE personnel that efforts have been made to increase access to linguistically competent services such as translation and interpretation. <u>Family members felt</u> there has been some improvement in terms of linguistic competence. They also provided feedback on ways to increase racial, ethnic, cultural, and linguistic competence.

Illustrative quotes:
- Family member: *"…putting things into a language is one thing. You can have things in English or Spanish and still feel overwhelmed. Too much jargon. Paying attention to the other variables is important to get through. Education and economic level. Speak to me like a person not a scientist."*
- Family member: *"Provide not only language access, but culturally sensitive language access to information about the different processes and supports available."*
- RC director to the question, *why did your Regional Center decide to submit a proposal for the SAE program*: *"One of the weaknesses that we had as we interviewed our community, was not having our material well translated. A big focus was making sure that we had our access points as easy to understand as possible. We broke it down to the simplest terms, so that people would be able to get and understand what we were, who we were, how we could help."*

<u>SAE personnel's comments aligned</u> with those of family members who noted that efforts were in process for increasing linguistic competence, but it could get better. For instance, they explained that by taking the time to understand the nuances of language barriers, the SAE projects implemented linguistic strategies that were tailored rather than generic. As a result, indigenous languages were included in language-focused initiatives such as on-demand educational videos and translated materials.

<u>**Excerpts of data triangulated on theme 1**</u>

When asked about *culturally competent approaches used to implement the grant, specifically in supports, services, and project activities*, only a small percentage of RC directors and SAE project managers stated that their initiatives focused on increasing **culturally representative staff** (listed by 22%

of RC directors, n=18, and 25% of SAE project managers, n=16) and **mitigating disparities at the family level** (listed by 17% of RC directors, n=18 and 19% of SAE project managers, n=16). SAE personnel and family members talked about the importance of making sure that supports and services are culturally and linguistically competent and provided recommendations.

Illustrative quotes:
- Cultural specialist to the question, *what recommendations do you have for DDS about disparities reduction: "Lack of available services (culturally and linguistically appropriate) is a huge problem. (There is the) need to increase rates to meet service needs. Quantity and quality of appropriate and diverse services is imperative! Huge shortage of services and even less for non-English speaking individuals."*
- Family member of service recipient to the question, *what recommendations would you make to DDS to improve supports and services for persons with developmental disabilities*: *"…access is the key… For us, as a Black community, that means not just focusing on language as the only disparity that exists... For me, it shifts at the foundation of it all. It's understanding and helping the different communities at the access points that are relevant to them, and being open enough to receive that information in even if it does not look like the way that government does things... Looking at that bridge, and not only creating a bridge but allowing us to walk back and forth across this bridge. They're starting to do it more with Service Access and Equity... It's only just beginning. I do appreciate the humble beginnings of where we are now."*

Some families highlighted that there is a need for increased diversity such as in staff and providers of color. In addition, families who were participating in the self-determination program felt it played a role in them receiving services that met their needs in a greater way.

Illustrative quote:
- Family member: *"…(my family's culture wasn't taken into consideration) until recently (with) the self-determination program… because (with self-determination) I'm making those choices for myself. I get to choose small businesses, African Americans. It's like having a PPO program as opposed to an HMO program… as far as what (the RC is) providing me. I would say the answer to that is no (my family's culture was not taken into consideration) because I had to fight a lot (in) asking for individuals who looked like my son."*

DDS staff members indicated that there were no explicit measures being used to consistently capture the extent to which activities are racially, ethnically, culturally, and linguistically competent.

Illustrative quote:
- DDS staff: *"We say we offer the service, but I don't think we have any specific measures. We don't have a standardized, "You got to pass this test with this set of vocabulary, and produce this to become competent." To have some kind of certification that we believe that you are delivering an accurate service."*
- DDS staff to the question, *what measures are employed by DDS to document the extent to which SAE grantees use culturally competent approaches in translation*: *"I don't know that there is something in place that we have as a grant program to document that, that our grantees are using culturally competent approaches."*

The lack of a structure for connecting data to outcomes was corroborated by SAE personnel, for instance when RC directors and SAE project managers were asked *whether their SAE grants were guided by theories of change or logic model*s. Less than a third indicated that they **had adopted a theory of change framework** (RC directors, 11%, n=18 and SAE project managers, 31%, n=16) or **had adopted a logic model** (RC directors, 11%, n=18 and SAE project managers, 19%, n=16).

Illustrative quotes:
- SAE project manager: *"…we developed our own framework to determine what kind of interventions would be needed, based on the individual level, supports, and then systemic needs."*
- RC director: *"How do you manage change, and how do you support the concept of making these changes? We started using them more when we created our DEI committee in-house. We created this committee. You really needed this leadership to occur so that you could get people on board…These frameworks that we used, these different guides that we got from the university, we tried to make sense of them for us and integrate them into what we're doing..."*
- SAE project manager: *"There were not a lot of illustrations of it, but there certainly were descriptions of proposed outcomes in terms of how many families would have a Promotora and would use their Promotora and if that would lead to a higher POS ratio so to speak."*
- CBO staff to the question, *how would you describe the effectiveness of your SAE grant project in decreasing disparities*: *"We will need accurate data from RCs to measure the effectiveness. We have done everything in the grants to be effective in reducing disparity."*
- Cultural specialist: *"There isn't always a lot of consistency across the RC's. Directives and language used in grants/grant measures is very vague and confusing."*
- CBO respondent: *"Possibly change reporting requirements to every 6 months, ensure outcome measures are priorities."*

In contrast, when asked if they *engaged persons with IDD and their families to evaluate supports and services provided by their SAE grant project*, 61% of RC directors said **yes** (n=18) and 75% of SAE project managers said **yes** (n=16).

Illustrative quote:
- SAE project manager to the question, *do you engage persons with IDD and their families to evaluate supports and services provided by the SAE grant project*: *"The whole thing, it was involving the individual and their family from the beginning to the end. We developed ways to measure out, that was really something that I wanted to do. We felt that it was important, so we developed ways to measure all of our outcomes. Again, I think that that's one of the reasons why our data continues to be easy to understand and shows the progress that we've made. That was engaging families from the beginning, as soon as the enhanced service coordinated. The first concept that they had was to do a pre- survey with the family to understand their level of knowledge regarding the regional center system. It was a very clean meeting. That was the main purpose of that meeting..."*

Theme 2: SAE grantees have already initiated efforts in addressing some inequities, but more is needed:

On theme 2, triangulated data revealed there was agreement by families, DDS staff, and SAE personnel that the SAE grants were helping RCs make progress towards addressing disparities. However, families and other respondents revealed that much more is needed.

Illustrative quotes:

- RC director to the question, *why did your Regional Center decide to submit a proposal for the SAE program*: *"…we realized, recognized that our Native American population was not accessing our services. We knew through our connections that there were children and individuals on the reservation there that needed our services, but that there was an issue of trust...gaining trust of their community, so that they would reach out to us and access services. That was our focus. We hired a person who lived on the reservation up there, the [name of reservation] and she still works for us."*

- SAE project manager to the question, *why did your Regional Center decide to submit a proposal for the SAE program*: *"I was the one that suggested that we do the peer mentor cafes. It was because I had seen a similar model through another agency with parent cafes…I felt that it was a similar model that we could adopt and have a moment with our parents and our clients to sit down and talk and see if maybe, through conversations, we could get at some of the other root causes of why they're not using their services, why do they not trust their service coordinator, or anything else that could come up."*

- Cultural specialist to the question, *what do you view as the role of the cultural specialist in disparities reduction in the California IDD system*: *"The cultural specialist (CS) is the voice that continues to speak about disparities even when that topic isn't on the top list of priorities of a regional center. The CS is the one that focuses on addressing disparities with SAE grant projects, through targeted outreach, and meaningful collaborations."*

- CBO staff to the question, *how was your project designed to reduce disparities at the family level*: *"The participant is educated on navigating (name of project withheld for anonymity) from the perspective of an independent facilitator. This increases their knowledge for personal development and reduces disparities that they experience navigating the system, as they have the knowledge to successfully navigate. The cascade impact to the family and self-advocate is the improved quality of life from accessing services and supports."*

- DDS staff to the question, *what measures are employed by DDS to document the extent to which SAE grantees use culturally competent approaches in translation*: *"The only evidence that we would have with that is they identify the professional organizations that perform the translations. I know that in some of those translation projects, there have been committees and work groups that oversee the translation process to ensure that it's accessible for the communities in which they're intended to serve."*

- Family member of service recipient to the question, *were the supports and services you received available in your preferred language*: *"Sometimes, not all the time. For me it is important for example to receive the IPP in my language, but it always takes time and I cannot sign something that I do not fully understand."*

Excerpts of data triangulated on theme 2

<u>Family members felt</u> that inequities existed in the services available to individuals from groups that were diverse racially, ethnically, culturally, and/or linguistically.

> Illustrative quote:
> - Family member: "*Access to services and supports are difficult for non-English speak(ers) and persons who identify as Black or non-white.*"

<u>Among DDS staff members</u>, most (5 out of 6 respondents) felt the SAE grant had an impact on reducing disparities by increasing the knowledge families had about RC supports and services.

> Illustrative quote:
> - DDS staff: "*The overall impact in reducing disparities, so far, I think that the connector projects have been able to connect a lot of families to generic and regional center services. In terms of the family education projects, I think that a lot more families have knowledge of the regional center system as a result of those trainings.*"

<u>SAE personnel felt</u> they had designed the SAE grant projects to address disparities and they were actively applying those funds to initiatives designed to reduce disparities. For instance, among respondents to the question, *How important is the grant program to your Regional Center's efforts to decrease disparities among persons with IDD across racial, ethnic, and linguistic groups?* 83% of RC directors (n=18) and a similar 88% of SAE project managers (n=16) felt that SAE grants were playing a **very important** or **important** role in helping the RCs address disparities.

> Illustrative quotes:
> - RC director: "*… we have tried before without the grant, but when you don't have dedicated funding, dedicated folks doing certain things, it's going to be set on the side.*"
> - SAE project manager: "*Very important. The reason why is because this is extra money that is not allocated in the budget and, like I say, is makes my dreams come true. That can provide and do more specific things that we don't have a budget for.*"

Similarly, CBO survey respondents indicated that they felt *the SAE grants were designed to reduce disparities* by **providing education and training** at the **family level** (66%, n=32), **individual level** (44%, n=32), and **community level** (23%, n=31)

> Illustrative quote:
> - CBO survey respondent: "*Parent navigators… help individuals and families access Regional Center services, both through initial application, and troubleshooting when more services are needed.*"

Theme 3: There is a need to build capacity in SAE funded organizations, RCs, and CBOs overall so that caseloads can be decreased and staff be well trained:

<u>On theme 3, triangulated data revealed</u> that all respondent groups felt RCs needed to increase capacity to support the needs of families. They also suggested that staff and providers should be allocated more manageable caseloads. Families made additional suggestions including: work to retain and increase the capacity of service coordinators; increase staff members' competence on topics of racial, ethnic, linguistic, and cultural diversity; and train all groups on the supports and services available to families.

        Illustrative quotes:
- RC director to the question, *why did your Regional Center decide to submit a proposal for the SAE program*: *"I would say it was definitely expanding our capacity. About 60 percent of our service coordinators are bilingual and bicultural. I would definitely say that it was expanding it in a formalized fashion."*
- SAE project manager to the question, *why did your Regional Center decide to submit a proposal for the SAE program*: *"When we were looking at applying for the grant initially, it was with this idea in mind that perhaps by having a reduced caseload, service coordinators would be able to make a bigger difference in regards to assisting families with accessing needed services, specifically in the court supports as well. That was, I think, the original idea of our project."*
- Cultural specialists to the question, *what recommendations do you have for DDS about disparities reduction*: *"Enhance better collaboration between RCs and CBOs that are funded through SAE grants. (There was a) lack of communication and accountability. Families were provided inaccurate information which could lead to negative relationship between RC & family."*
- CBO staff to the question, *what were the most significant challenges in implementing the SAE grant program*: *"First of all, the lack of staff… An entire grant program was on our shoulders. That was separate from everything else we do. It was atrocious."*
- DDS staff to the question, *root causes or factors that contribute to disparities in California's system for person with IDD and their families from racially, ethnically, culturally, and linguistically diverse groups* *"I think that the regional center itself causes a lot of the issues and problems in disparities themselves, and that could be attributed to service coordination, that whole team. They are the first point of contact with families and they of course, have their own biases."*
- Family member of service recipient to the question, *how would you rate the quality of the supports and services you received*: *"As far as regional center, our service coordinator's fairly new so she doesn't know or is able to share a whole lot with us because she's still learning, but she has been receptive to our questions where she will talk to her supervisor and find out if there's something we have a question about."*

<u>Excerpts of data triangulated on theme 3</u>
<u>Family members noted</u> recurring themes that staff members, particularly service coordinators, needed reduced workloads; deeper knowledge of the supports and services available to families; and increased competence on topics how to address the needs of individuals of racially, ethnically, linguistically, and culturally diverse groups . When asked, *were the supports and services you received available in ways that took your family's culture into consideration*, families provided examples where their cultures were not considered.

Illustrative quotes:
- Family member: "*…when I think about regional center, there isn't anyone in our regional center that looks like us to give or to provide services. That's still a present challenge.*"
- Family member: "*whenever we have someone new, I speak to them before they even see my son. I let them know the rules of our house. If they can't adapt to that with their services, then we'll need someone else… we would have people come in and try to tell me, "This is what we're going to do… They wouldn't ask for any input from us. (For example) In our household, he's not allowed to talk like that. He doesn't speak to elders that way." They were like, "Oh, well, you don't have to say Miss or ma'am or sir." I was like, "Yes, he does. That's us." It was like, "I don't care what everyone else is doing, but this is the way we do things." It was always what they (the providers) considered small and (they felt) that he (my son) didn't have to do.*"

In a similar way, it was felt that the capacity of providers needed to increase so that families could access services once they were approved to receive them.

Illustrative quotes:
- Family member: "*Caseload reductions. Service coordinators simply cannot do the work they are required to do with the current caseloads they carry.*"
- Family member: "*the coordinator that I have, she doesn't really communicate with me on the services. What I'm doing is I'm trying to just figure out what other services that would benefit her (my daughter). It's like I'm out there searching.*"
- Family member: "*(Services and supports were) useful because anything you receive helps, but there are not enough services that are needed (that are) able to be accessed. Need vs access.*"

DDS staff members felt there is room for growth across all levels including within RCs, among staff members, in SAE personnel, by families, and within communities.

Illustrative quotes:
- DDS staff member: "*We need more representation, we absolutely do, at the leadership level as well. I know the regional centers are trying to hire more service coordinators that match the communities they serve. Again, if management and the higher executives don't necessarily reflect that community, we also see some biases and some other things. We need more representation, absolutely.*"
- DDS staff member: "*I think we have a team that wants to improve what we're doing and a team that just is willing to look at other alternatives of how to do things, and what might be needed. Ultimately, it hopefully becomes something that we can use to educate regional centers, to educate legislature, and maybe to build out budget proposals.*"

SAE personnel agreed with families and DDS staff that capacity is an area that needed to be addressed. They felt that due to the size of staff and providers' caseloads, it was difficult to adequately serve individuals and families. When asked about specific tasks such as *collecting, analyzing, and reporting on disparity data for the SAE program*, the vast majority of partners indicated their current capacity was **low** to **moderate** (72% of RC directors, n=18 and 78% of SAE project managers, n=16). These capacity challenges were highlighted across the range of services, supports, and activities RCs engage in.

Illustrative quotes:
- RC director: *"Having caseloads at 95 and 100 when they're statutorily supposed to be at 62 and 66 is a direct connection, and a root cause of disparities. I've sat with our bilingual/bicultural social workers who talk about the days when they used to be able to have enough time to go to an IEP and support the family in battling with the schools to get what they are entitled to from special education. You can do that at 60 if you're serving 60 people. If you're serving 100 people, you cannot do that because there's too many crises going on."*
- RC director: *"The number of employees service providers need that have these other language abilities, these other cultural understandings...I don't think we can put a number on it. I don't think we really know, but we're always looking. Our families are always saying, "When are you going to find more Korean OTs [occupational therapists]? When are you going to find more Russian PTs? [physical therapists]"? When you have monolingual families, and those professions that I just mentioned, if you go into the universities, you're going to find Caucasian. You'll probably find Latinos. Whether you find a lot of other languages, because they're not recruiting."*
- CBO survey respondent: *"The disparity for African American/Black Families is beyond what the numbers show. There is a disparity and injustice not only to families who are clients of the RC services but there is a lack of access to the information to even gain access into this system of care. The system seems to put this huge focus on linguistics as if that is the only disparity that exists."*

SAE project managers described initiatives designed to increase capacity to serve communities that had historically been underserved. For instance, respondents felt that providing educational videos that families could access at any time, would help increase the capacity of programs and families and could potentially decrease disparities. SAE project managers also noted additional supports such as parent navigators and virtual training initiatives created to help meet the needs of families and individuals. When asked *whether or not their SAE project led to an increase in: availability of supports and services* and to identify *the most significant outcome from their SAE project in terms of disparity reductions*, SAE project managers identified several areas including the parent navigator programs and their virtual trainings.

Illustrative quotes:
- SAE project manager: *"The availability, they were more aware, thanks to the navigator program and then culturally appropriate programs as well. The families were more aware of these because these people were already embedded in the community…"*
- SAE project manager: *"Our online virtual trainings…we're getting a lot of feedback about, for example…the best one for me is, "I didn't even know the service existed." Certainly, planting seeds about expanding individuals' knowledge of different service options that they could access. The other one is, 'I didn't know that I could appeal a service.'"*

Theme 4: Services and supports should be designed and allocated through the lens of family members as empowered advocates:

On theme 4, triangulated data revealed that family members, DDS staff, and SAE personnel all expressed a desire for service recipients to receive the resources needed to achieve the quality of life based on their needs and interests. Family members felt that there were unnecessary barriers and gatekeeping efforts they had to fight against for services. SAE personnel and family members attributed these challenges to a lack of knowledge by families on how to navigate the system, much of which is caused by the complexity of procedures required by the RCs. However, both DDS staff and SAE personnel acknowledged some areas where internal practices and procedures contributed to families not accessing services at greater levels. In many cases, respondents provided examples of efforts that were under way to address and remove barriers.

Illustrative quotes:
- RC director to the question, *why did your Regional Center decide to submit a proposal for the SAE program*: *"The idea was if folks have a better understanding of the services that are available to them then that would help with access to those services. It would allow our service coordination staff to better assist those families that have experienced disparities in the system."*
- SAE project manager to the question, *why did your Regional Center decide to submit a proposal for the SAE program*: *"We focused a lot on trainings with the individuals that we support. We focused the trainings around transition points. For example, individuals transitioning from early start into children's units over three. Then, children transitioning from high school into adult, and provided a lot of...We had seminars and trainings for families to educate them about changes and service options."*
- Cultural specialist to the question, *how does your Regional Center define equity for the population of people with IDD and their families*? *"Access to and utilization of services that meets their individual needs. Individuals with IDD should have equal access to opportunities for supports and services to live the life they choose."*
- CBO staff to the question, *how was your project designed to reduce disparities at the family level*: *"Through training (name or information withheld for anonymity) with new skills and resources, families are impacted. (Name or information withheld for anonymity) can help families with systems navigation through the regional center. (Name or information withheld for anonymity) are also developing new social media and printed materials to assist families. (Name or information withheld for anonymity) are likelier to refer families to Regional Center and help them advocate and ask for services."*
- DDS staff member to the question, *extent to which the SAE program was designed to reduce disparities such as at the systems level*: *"We have seen that. I don't know that the whole program was designed to impact that, but I think it has had some effect on organizational and systems changes. I think that the success of individual programs has made regional centers look a little bit more holistically at their operations. Maybe there was an indirect effect of the initial purpose of the grant program."*
- Family members of service recipients to the question, *based on your own experience, would you recommend the supports and services provided through Regional Centers to another family? If yes, why*: *"Not a fair question. If you are thirsty, would you not drink water if available?"*

Excerpts of data triangulated on theme 4

Family members expressed high levels of frustration regarding the complexity of the RC system. Some respondents felt that the root cause was not the system itself but was due to a lack of knowledge by staff and an underlying culture that did not view families as rightful recipients of the resources available through the RCs. Citing those reasons, families perceived the process as a constant fight to receive services. Almost half of responding families (47%, n=17) rated the *supports and services received from the RCs* as **somewhat acceptable**. In their comments, families stated that they gave this rating because of the difficulties they faced to receive the resources their family member(s) needed.

> Illustrative quote:
> - Family member: *"It's a struggle to get these services approved by RC first. Once they decide to approve the support, it's a struggle to get the adequate personnel or a schedule that works for everyone. The way the system is set up right now fails at every turn."*

A similarly rating of **fair** was given by 44% of families (n=16) for the *quality of the services received from the RCs.*

> Illustrative quote:
> - Family member: *"I've had two annual meetings with my case manager and she has not fixed, has not followed up, and seems fine with me not receiving services yet."*

In contrast, 44% of respondents indicated that the *supports and services* were **useful** and almost one third (31%) felt they were **very useful** (n=16). In their comments, families clarified that these ratings were given because the resources were needed and they made an impact for the individuals being served, not because the RCs provided services in a useful way. Similar clarifications were made when families were asked if they would *recommend the RCs' supports and services to other families*.

> Illustrative quote:
> - Family member: *"Yes, and only because we need the support as parents and it is out there - it is very overwhelming otherwise - and we push for self-determination. A family is overwhelmed with caring and supporting their individual - the systemic supports go a long way to relieve the pressure and stress."*

DDS staff members noted that the system is working to adopt a greater focus on understanding and meeting the needs of diverse individuals with IDD and their families. Specifically, when asked to identify *root causes or factors that contribute to disparities*, DDS staff identified some of these factors.

> Illustrative quote:
> - DDS staff member: *"The fact that we have an old system and it was designed without diversity at the table when they were deciding and designing things. It worked well for a small amount of people, or not a small amount, but a specific type of people per se. Now that we have a diverse program, some of those things that we came up with a long time ago don't necessarily fit for everyone, are not culturally appropriate, or is just something that the families (are) not interested in doing."*

<u>SAE personnel</u> provided varied perspectives on why families faced challenges in navigating the system and in receiving services. Generally, RC directors and SAE project managers identified root causes such as language barriers, the need for families to be more knowledgeable about navigating the system, and the great level of need compared to the limited capacity within the RCs. Cultural specialists and CBOs also discussed efforts to increase families' knowledge about navigating the system. These groups felt that removing barriers required understanding the full needs of individuals and families as well as teaching them how to advocate. Respondents discussed the importance of making sure everyone is treated fairly, ensuring access to needed services, and increasing cultural proficiency so those who need more support can receive it.

> Illustrative quotes:
> - SAE project manager: *"These are systems that weren't built with people of color in mind, minorities, people who don't have access to education or wealth. These systems have been built by people who had certain privileges…"*
> - CBO survey respondent*: "As it states within our name, our objective is to integrate families from within the perspective of the community into the systems of support. We meet with RC directors and senior staff on a monthly basis to discuss issues and areas of concerns as well as best practices. In addition, we collaborate and meet regularly with statewide organizations."*
> - CBO survey respondent*: "…We also have supported emerging CBOs in an incubator model, helping the CBO leaders launch their organizations. Our project levels the playing field for parent-run CBOs in California, and this changes the DD and other human services systems."*

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