



Independent Evaluation of the Service Access and Equity Program

California Department of Developmental Services

Final Report

Submitted by Georgetown University National Center for Cultural Competence

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Executive summary

Introduction

In 2016, the California Assembly enacted legislation (AB X2 1) to establish the Service Access and Equity (SAE) Grant Program. This grant program allocated \$11 million dollars annually to the Department of Developmental Services to assist Regional Centers to implement strategies within their respective centers that reduce disparities in purchase of services among the state's racially, ethnically, culturally, and linguistically diverse populations. This legislation (AB107) was amended in FY 2017-2018 to allow community-based organizations to receive funds from the SAE Grant Program.

In 2021, DDS issued a request for proposal to conduct an independent evaluation of efforts to advance equity and reduce disparities in the state's developmental disabilities services system, specifically focusing on the impact of and future direction for the SAE Grant Program. The Georgetown University National Center for Cultural Competence (NCCC) and Mission Analytics Group (NCCC-MA Team) were awarded a contract on March

11, 2022, to conduct the independent evaluation focused only on those Regional Centers and community-based organizations that were funded during fiscal years 2018-2019 and 2019-2020. It is important to note that FY 2019-2020 was at the height of the devastating effects of the COVID-19 pandemic. ***This global public health emergency had an adverse impact on the implementation of SAE Grant Programs for FY 2019-2020.***

The California State Legislature and the Department of Developmental Services (DDS) are commended for centering efforts to address racial, ethnic, cultural, and linguistic disparities for persons who experience intellectual and developmental disabilities, their families, the communities in which they live, and the system that provides them with supports and services. The NCCC-MA Team asserts with great confidence that there is no other state nor territory that has enacted legislation and allocated fiscal resources to begin a process to confront and address racial, ethnic, and linguistic disparities in intellectual and developmental disabilities. California leads the nation both in legislation and in allocation

of funding toward this end.

Disparities reduction, and corresponding initiatives to address them within DDS are not limited to the SAE Grant Program — nor should they be. One dedicated grant program, even funded at \$11 million dollars annually, simply is not capable of addressing the entrenched and complex array of disparities that disproportionately affect persons who experience intellectual and developmental disabilities and their families from specific racial, ethnic, and linguistic groups residing in California. While disparities reduction and equity are related, they are not the same. DDS understands this. The independent evaluation conducted by the NCCC-MA Team documents numerous other efforts within DDS to decrease disparities and advance equity. Moreover, an analysis of root causes of racial, ethnic, and linguistic disparities within the context of intellectual and developmental disabilities services is necessary system-wide, not just within the SAE Grant Program, including other California State Departments that deliver services to this population and their contractors and vendors.

While this evaluation documents the accomplishments of the program, it also critically assesses the areas where improvement can be made. Evaluation findings fully support continuation of the SAE Grant Program and provide concrete recommendations to strengthen the program which can be implemented in short, intermediate, and long-term efforts to achieve the goals commensurate with the legislative intent to reduce disparities and increase equity for persons who experience intellectual and developmental disabilities from identified racial, ethnic, and linguistic groups. It is important to acknowledge the commitment of DDS staff to restructuring the SAE Grant Program based on recommendations of this independent evaluation. DDS leadership has already incorporated a number of recommendations put forth by the NCCC-MA Team into the 2023-2024 SAE Grant cycle before this final report was submitted on 8/31/23.

This executive summary (pages 1–11) provides key elements of the comprehensive final report submitted by the NCCC-MA Team to fulfill terms of the contract with DDS.

Background and context

At the time the request for proposal was issued by DDS, the SAE Grant Program had been implemented for five years, yet it had never been evaluated. Publicly available data from DDS, testimony provided to the California State Senate and Assembly, and widely publicized reports conducted by advocacy organizations and social justice groups document persistent challenges of racial, ethnic, and linguistic disparities that affect persons with lived experience of intellectual and developmental disabilities (IDD) and their families across the state. When compared with other states, California has a unique advantage through enacted legislation and a dedicated budget that place high priority on decreasing racial, ethnic, and linguistic disparities among persons with IDD through the SAE Grant Program. It is important to note that DDS leadership and staff are committed to advancing equity within the IDD system, and that the SAE Grant Program **is only one** of many disparities reduction policy and service initiatives implemented by the Department since the grant program was launched.

Disparities based on race, ethnicity, languages spoken (other than English), and geographic locale are the well-documented products of inequities across this nation's human/social services, health and mental health, and education systems. **Such disparities are not new — neither are they unique to California nor to developmental disabilities systems.** What is unique to developmental disabilities systems nationwide is how they lag far behind in defining exactly what equity means, how equity is manifested in supports and services, how to measure efforts to achieve equity across the complex array of supports and services within these systems, and how to advance equity in partnership with those populations and communities disproportionately impacted by such disparities.

Literature reviews reveal that historical and present-day disparate treatment of persons who experience developmental disabilities based on race, ethnicity, and gender include but are not limited to health care, mental health care, education, housing, employment, childcare, law enforcement, and the justice system. This literature is largely descriptive and devoid of evidence-based practices focused on

disparities reduction. ***Most notable is that very little of this literature defines equity within the contexts of developmental disabilities in general, and in state-operated systems of supports and services in particular.***

Disparities framework

For this evaluation the NCCC-MA Team used the *NCCC Disabilities Disparities Framework*, (Goode, 2017) to examine the array of disparities experienced by persons with developmental disabilities and their families who often need supports and services across multiple systems. The NCCC-MA Team used this framework to develop queries that probed — disparities in what?

- **Availability** of supports and services including the array, type, and intensity.
- **Accessibility** of supports and services such as geographic distribution, hours of delivery, technology, language access, accommodations, and universal design.
- **Acceptability** which principally involves system capacity to plan, deliver, and evaluate culturally and linguistically competent supports and services to diverse populations across the life course.
- **Quality** of supports and services across diverse populations and communities. Quality in the context of this framework is defined as the totality of features and characteristics of supports and services that enable systems and organizations to be responsive to and satisfy the interests and needs of a given population.
- **Utilization** rates across culturally and linguistically diverse populations including the types of supports and services.

It is well documented that resource allocation in both the public and private sectors are contributing factors to disparities. Goode's Disparities Framework depicts the correlation between the levels of policy and resources, the array of supports and services across multiple systems, and the full participation of persons who experience developmental disabilities in all facets of community life. Each of the three levels are inextricably linked, critical to the evaluation of the SAE Grant Program, and can be applied to the California developmental disabilities system.

Terms and language used in this final report

This report reflects the NCCC-MA Team's intentional use of language. There are differences in beliefs and practices about person-first or identify-first language related to developmental and other disabilities. The NCCC-MA Team respects each person's right to choose how they self-identify and the terms and language they choose to convey their identity or identities. This final report will use the terms person(s) who experience intellectual and developmental disabilities (IDD), person(s) with lived experience of IDD, population of people with IDD, people or person(s) with IDD, and individual(s) with IDD.

Moreover, identity by race and ethnicity varies significantly in how a person or group self-identifies compared to how data are collected and reported in human service systems. The NCCC-MA Team refrains from using the terms minority or minority populations. When a population is known by race and/or by ethnicity, that designation will be used. California is designated as one of the most racially, ethnically, culturally, and linguistically diverse states in the U.S. and racial and ethnic identities are numerous. California is designated as a "majority minority" state by the U.S. Census which means the state's population is composed of less than 50% non-Hispanic White. The narrative, figures, charts, and tables presented in this report will use the following terms based on data source (i.e., self-identified and administrative data sets for the 2018-2019 and 2019-2020 grant cycles): race - African American or Black, American Indian or Alaska Native, Asian, Pacific Islander, Native American, White (Hispanic), White (non-Hispanic), Other (not specified), Other – Indian, Other – Mixteco, Other – two or more races, Unknown; ethnicity – Hispanic, Hispanic/Latino, Hispanic/Latinx, and Non-Hispanic.

Evaluation design

Purpose and objectives

The overall purpose of the evaluation was to independently evaluate the effectiveness of the California SAE Grant Program. To focus the evaluation, several objectives guided this work and are identified below.

Project objective 1

Analyze the impact of the SAE Grant Program using data generated by the grantees and administrative data from DDS to identify changes that would improve the grant program's effectiveness in increasing access and reducing disparities.

- **Sub-objective 1.1.** Characterize the projects and their outputs and outcomes.
- **Sub-objective 1.2.** Measure the impact of these projects on service patterns and expenditures.
- **Sub-objective 1.3.** Use the results of the analysis to identify promising strategies in the grant program.

Project objective 2

Develop qualitative and quantitative measures designed to assess the impacts and outcomes for future SAE Grants administered by California DDS.

- **Sub-objective 2.1.** Recommend quantitative and qualitative outcome/impact measures based on the type and focus of the project and the proven methods that reduce disparities at the individual, family, community, organizational, and systems levels.
- **Sub-objectives 2.2.** Recommend outcome/impact measures are feasible for grantees with different capacities for and expertise in data collection and analysis, different resource levels, and different stages of implementing cultural and linguistic competence at the organization level.

Project objective 3

Develop recommendations for metrics that can be used to prioritize areas of focus, populations, and interventions that will have an impact on disparities reduction at the individual, family, community, organization, and systems levels.

- **Sub-objectives 3.1.** Conduct structured interviews with Regional Centers Directors and SAE Project Managers to elicit information on the implementation and outcomes of their funded programs.
- **Sub-objectives 3.2.** Conduct small group listening sessions for families to elicit their experiences and insights on disparities and equity within the California IDD system of services and supports.
- **Sub-objective 3.3.** Conduct structured interviews with staff of the Department of Developmental Services to: 1) review the Department's vision for equity and disparity reduction; 2) elicit their views on the contributing factors to disparities including root causes; 3) ascertain view and evidence of the overall impact of the SAE Grant Program; 4) gauge the Department's willingness and authority to rethink how the SAE Grant Program is structured, administered, and evaluated; and 5) explore the feasibility of changing approaches and components of the SAE Grant Program based on evaluation results and recommendations.
- **Sub-objective 3.4.** Use Goode's *Disability Disparities Framework* as a basis for questions to administer a survey for CBOs and conduct listening sessions with Regional Center Cultural Specialists and CBOs that include but are not limited to: 1) describe the role they play in disparity reductions within the California IDD system of supports and services; 2) define equity within the context of IDD supports and services; (3) describe the root causes of racial, ethnic, and linguistic disparities; and (4) describe the role and impact of the SAE Grant Program; and (5) offer recommendations to enhance the SAE Grant Program.

Evaluation methods

Mixed methods (quantitative and qualitative) were used to evaluate the SAE Grant Program. Careful consideration was given to the most appropriate methods for each stated objective. Methods included analysis of quantitative administrative data, focus groups, listening sessions, literature review, structured interviews, and surveys. Key constituency groups were engaged in various aspects of the evaluation process to ensure relevant voices were heard and important data was collected. These included: individuals with lived experience, families, community-based organizations, Regional Center directors, SAE Project Managers, Cultural Specialists, and state DDS agency personnel. The full report provides details of the numbers of constituents involved in each component of the overall evaluation. The activities of this project were reviewed and approved by the Georgetown University Institutional Review Board (IRB).



Summary of key finding by objective

Findings for objective 1

This objective focused on analyzing the impact of the SAE Grant Program using data generated by the grantees and administrative data from DDS to identify changes that would improve the grant program's effectiveness in increasing access and reducing disparities. Key findings from the quantitative analysis of administrative data include but are not limited to:

- A little over half (54) of the SAE projects funded in 2018/19 and 2019/20 had project objectives that mapped to increased Early Start assessments, POS expenditures, or respite care expenditures and also had focal populations that could be identified in administrative data.
- These 54 projects reported serving more than 142,000 individuals, representing 75 combinations of Regional Centers and race/ethnicity groups. Promotora Projects represented the largest share of these projects, followed by outreach projects, which were most likely to focus on Early Start assessment.
- By 2021/22, children from SAE focal groups in Regional Centers where SAE projects focused on Early Start assessment were more than twice as likely to be assessed for Early Start compared to non-Hispanic White children from the same regional centers (controlling for population sizes). Only a third of the SAE projects were focused on groups that were less likely to be assessed as of 2017/18. For those groups, disparities relative to non-Hispanic White children were reduced but not eliminated.
- In Regional Centers where SAE projects focused on increasing POS expenditures (other than for residential care), the share of individuals with any POS expenditures increased more between 2017/18 and 2021/22 for SAE focal groups compared to non-Hispanic White individuals in the same age brackets.
- Average POS expenditures also increased more for SAE focal groups, but the increases were not large enough to eliminate the disparities in POS

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expenditures. By age category, disparities were largest for adults from the SAE focal groups.

- Between 2017/18 and 2021/22, both the share of individuals with respite care and the average respite care expenditures rose faster for SAE groups than for non-Hispanic White individuals in regional centers where SAE projects focused on increasing respite care.
- Changes were larger in Regional Centers where SAE projects had been in place the longest.

A full accounting of Objective 1 including SAE project characteristics, methods, analysis of administrative data is presented on pages 28-36 of the narrative report.

Findings for objective 2

This objective focused on the need to develop qualitative and quantitative measures designed to assess the impacts and outcomes for future SAE Grants administered by California DDS. Key findings related to the measurement of effective outcomes of SAE projects include but are not limited to:

- DDS did not have grant-wide program measures to assess the impact of the SAE Grant Program on disparities reduction for the 2018-19 and 2019-20 grant cycles. It is important to note that DDS does currently provide [guidance](#) on how to report data that show progress and outcomes of grant activities in the 2023-2024 grant cycle.
- The focus of the grant categories that were funded (e.g., translation, advocacy, parent training and engagement) do not consistently show a direct correlation and measurable impact on disparities reduction.
- There is limited capacity among grantees (Regional Centers and CBOs) to collect and analyze the types of data that demonstrate impact on disparities reduction.
- Neither an official definition of equity nor a blueprint and guidance to advance the concept and practices of equity within the SAE Grant Program were in place for the 2018-2019 and 2019-2020 grant cycles.
- Measures need to be differentiated based on a shared understanding and acceptance of definitions of disparities and equity — and specific

theories of change for decreasing one (disparities) while simultaneously advancing the other (equity).

A full accounting of Objective 2 including methods, approach justification, and findings are presented on pages 37-42 of the narrative report.

Findings for objective 3

This objective is focused on developing recommendations for metrics that can be used to prioritize areas of focus, populations, and interventions that will have an impact on disparities reduction at the individual, family, community, organization, and systems levels. Key findings for this objective include but are not limited to:

- Regional Centers and CBOs sought SAE Grant projects to support and grow current efforts to advance equity, expand their outreach efforts, and to find new ways to incorporate underserved populations and underresourced communities that perhaps had not yet been a population of focus.
- An array of reasons was identified by Regional Center Directors and SAE Project Directors as to why disparities existed in their regions/geographic areas, including but not limited to:
 - » Lanterman Act which was created in the 1960's primarily due to the successful advocacy of White (non-Hispanic) families and the system was designed to serve that population.
 - » The service menu may not offer supports and services that are wanted (acceptable) that are responsive to and meet the interests and needs of racially, ethnically, culturally, and linguistically diverse persons with IDD, their families, and the socio-cultural contexts of the communities in which they live.
 - » Many families must juggle multiple competing demands and circumstance that require prioritizing and problem solving and accessing IDD services may not rise to the top priority when housing, transportation, and food insecurity needs are not being met.
 - » Too often services are provided by staff who are neither from nor knowledgeable of the diverse racial, ethnic, and linguistic communities



in their geographic locale which cause barriers and ultimately contribute to disparities in the acceptability, quality, and utilization of such services.

- Some Regional Centers were able to allocate more time to support their SAE Grant activities through an enhanced case management program which temporarily decreased the caseload size for several of their staff. This allowed the case managers to support persons with IDD and their families with generic services and supports that helped the entire family while also focusing on the person with IDD.
- Nearly all Regional Centers reported that they tried to incorporate elements of both culturally and linguistically competent approaches in their grant projects.
- Many Regional Centers found it challenging to gain the trust of the populations of focus due to historical racism and cultural beliefs and practices related to engaging with providers and services outside of the family units and communities in which they live.
- Only some of the SAE Grant activities and strategies were used to reach people with IDD and their families that were unknown or not receiving services through the Regional Center system.
- Regional Centers did not have adequate data systems and tools, or staff with the expertise or time needed to analyze the results of their SAE Grants.
- The data provided by DDS is reported as basic and focused on purchase of service (POS) with many important variables unreported (e.g., age, socio-economic status, and other cultural factors).
- Other measures are needed to demonstrate increases in service availability, acceptability, accessibility, quality, and utilization among people with IDD and their families disproportionately impacted by racial, ethnic, and linguistic disparities.
- Nearly all Regional Centers indicated that they either did not know about or did not specifically use a theory of change or a logic model to inform their grant projects.
- Across Regional Centers, no standard definition of disparity or equity existed, and neither was required in the guidance for the SAE Grant proposals.
- Regional Center respondents agreed that the SAE Grants should have a longer time frame. Most projects lasted about one year which was simply not enough time to determine if the activities of their SAE Grants would either begin or continue to benefit populations and communities of focus.
- Projects and outreach activities were limited in implementation because project activities were often added to the workload of existing staff who typically work a 9:00 a.m. to 5:00 p.m. business day.
- The ramifications of COVID-19 and the need to completely change from in-person activities to virtual cannot be understated. The COVID-19 pandemic significantly hampered outreach to people with IDD and/or their family members often due to lack of: 1) access to computers and/or understanding of how to access virtual platforms; and 2) trust by people with IDD and/or their family members was seen as a barrier to participation in supports and services.
- Nearly all Regional Center Directors reported a growth in their own and their employees' understanding of disparities, their root causes, and culturally competent practices.
- Families identified frustration regarding the availability of supports and services, often due to waitlists, vendor availability, and processing times. The term "denial by delay" emerged as a

recurring experience described by expressing their frustration with the delays and time lag.

- Navigating complex systems, especially for families lacking the resources and/or self-advocacy skills, posed a barrier.
- Most families expressed the need for greater cultural considerations that respect their values, traditions, and preferred languages in the provision of supports and services.
- Language access issues were raised, including: 1) limited availability of resources in languages other than English; 2) disparities in access to services for non-English speakers; 3) inaccurate translation and interpretation services that lacked accuracy and did not consistently capture the cultural and linguistic nuances in written documents and oral communication.

A full accounting of Objective 3 and sub-objectives 3.1–3.4 including methods, approach justification, data collection and analysis, triangulation report summary, SAE project report ratings, and findings are presented on pages 43-74 of the narrative report.



Recommendations: Metrics, measures, and SAE Grant priorities

Based on the extensive methods used in the evaluation to gather, analyze, and summarize data, the following recommendations that are grouped into four categories —

1. Grant focus,
2. Project structure,
3. Project types, and
4. Grant measures.

1. Grant focus

- ***Reduce the number of grant priorities by identifying areas of impact that have the greatest likelihood of reducing disparities.***

Careful consideration should be given to reducing the number of priorities by identifying areas of impact that have the greatest likelihood of reducing disparities and increasing access for the racial, ethnic, and linguistic populations of focus.

2. Project structure

- ***Define what equity is within DDS and the SAE Grant Program.***

Define the concept of equity, how to measure efforts to achieve equity across the complex array of supports and services within these systems, and how to partner with communities, populations, and families disproportionately affected by inequities. Establish a shared definition and framework for advancing equity, so that it is easily understood within the service provider network and among key constituency groups in the state. The grant program and guidance must provide clarity on the difference between disparity reduction and equity going forward to ensure consistency and integrity across applicants and funded grantees.

- ***Establish a requirement that SAE Grants will be issued to Regional Centers if they partner with a community-based organization.***

Revisit how resources are distributed within the SAE Grant Program to advance equity. This approach benefits CBOs and Regional Centers by adhering to two National Center for Cultural Competence principles of community engagement: (1) Communities should economically benefit from collaboration; and (2) Community engagement should result in the reciprocal transfer of knowledge and skills among all collaborators and partners.

- **Refine the focus on disparities reduction.**

The structure of the current SAE Grant Program and guidance are largely based on disparity populations defined by race, ethnicity, and languages spoken. Since disparities are the product of inequities, it is important that the SAE Grant Program is structured to respond to the question – *Disparities in what?* Using a disparities framework that is available in the published literature – enables DDS and grantees to discern if there is a disparity in availability, accessibility, acceptability, quality, and utilization of supports and services at the individual (persons with lived experience of IDD), family, community, organizational, and systems levels?

- **Make better use of the current evidence in disparities reduction including requiring cultural and linguistic competence.**

The SAE Grant guidance should require that culturally competent and linguistically competent practices are embedded throughout each project. Cultural competence and linguistic competence are evidence-based practices that reduce disparities. Grantee applicants should be required to define cultural competence and linguistic competence and how such practices will be applied in their projects.

- **Increase the length of time that SAE Grant projects are funded linked to community accountability and performance.**

Disparities reduction is a developmental process that occurs over time, as such, longer-term focused implementation and evaluation of grants areas that have the greatest likelihood or track record of reducing disparities should be used going forward. Strongly consider awarding one-year planning grants with up to three-four years

of additional funding for implementation and evaluation.

- **Require a logic model and a theory of change framework for all SAE Grant projects.**

DDS should provide a logic model that instructs grantee applicants on how to graphically depict the relationships among the resources, activities, outputs, outcomes, and impact of the SAE Grant Program and proposed projects. Grant applicants should be encouraged to use a theory of change framework, which entails a comprehensive description and illustration of how and why a desired change is expected to happen in a particular context.

- **Develop more effective measures and evaluation methodologies to assess the SAE Grant Program.**

Begin a process starting with 2023-2024 grant guidance to require and support measures to document the outcomes and impact of the SAE Grant Program more effectively. This may include but is not limited to: (1) identifying quantitative and qualitative measures and metrics that document disparities reduction at the individual (person with lived experience of IDD across the life course); (2) requiring grantees to collect and report data that demonstrate impact and outcomes that do not solely rely on POS; and (3) assuring the meaningful participation of constituency groups involved/served by the grant projects in community-engaged, culturally and linguistically responsive evaluation processes to elicit their experiences.

3. Project types

- **Define approved project types.**

Reduce the number of priorities by identifying areas of impact that have the greatest likelihood of reducing disparities and increasing access for the racial, ethnic, and linguistic populations of focus. Continue to fund project types as pilots to identify promising practices. The NCCC-MA Team offers suggestions for the four project types listed in SAE Grant guidance at the time the evaluation was conducted.

DDS descriptions of project types for the 2018-2019 and 2019-2020 grant years:

- i. **Education and Training:** Increase self-advocate/family knowledge about topics relating to service access, the Regional Center system, leadership development, business development, advocacy, independent facilitation, implicit bias, and developmental disabilities.
- ii. **Engagement and Outreach:** Increase community awareness and engagement through outreach activities (e.g., informational presentations, fairs, developmental screening events).
- iii. **Community Connector:** Utilize community leaders, family members, and self-advocates to provide individualized support to assist families with accessing services. Promotora, Navigator, Peer/Parent Mentor or Independent Facilitator are examples of community connector projects.
- iv. **Workforce Capacity and Development:** Diversify and increase cultural and linguistic competency of Regional Center and/or service provider staff, expand available workforce, and promote business ownership from diverse communities.

Recommendations Education and Training

- The provision of education and training may not result in meaningful increase in POS, particularly in the short-term. Regional Centers and CBOs would need to measure and prove the direct correlation between a training, advocacy, leadership, or business development activity and an increase in service access or disparities reduction.
- Education and training activities are an important resource to persons who experience IDD and their families as well as CBOs. The NCCC-MA Team recommends that DDS should continue to fund this project type but it should not be subjected to the stringent metric of POS due to the complexity and cost associated with proving outcomes and impacts by race, ethnicity, and language based solely on expenditures for previously stated reasons.
- If the project type continues to include staff training, emphasis should be placed on



ensuring supports and services are culturally and linguistically competent particularly for the populations of focus disproportionately affected by disparities. If the project type continues to include families, emphasis should be placed on ensuring support to assist families navigate the complex DDS system (from awareness, eligibility determination, complaint and dispute resolution processes, service selection and use, and providing feedback through evaluation). Using an equity lens, encourage and fund projects that hire families as navigators.

Recommendations Engagement and Outreach

- Community engagement and outreach are essential to inform culturally and linguistically diverse families and communities about DDS supports and services throughout the life course. The NCCC-MA Team recommends continuing to fund this project type. Similar to Education and Training, this project type may not yield the data required to satisfy POS. Grantees will need to be able to measure and demonstrate a direct correlation between the activities (informational presentations and fairs) that resulted in increased service access or a reduction in disparities.
- Developmental screening events have more promise, yet the same organizational capacity will be required to collect and track data

from families to determine if children were determined eligible and actually received supports and services. It will be necessary to differentiate project requirements because Regional Centers have different responsibilities and resources when compared to CBOs.

Recommendations Community Connector

- The NCCC-MA Team supports continued funding of this project type. Priority funding should be given to those racial, ethnic, and linguistic groups (i.e., monolingual in languages other than English, limited English proficiency as defined by US Census, ASL or other sign language users) that experience the greatest percentage of disparities in service access. While the demographic make-up may indicate a larger population of a particular racial or ethnic group, smaller population groups may be inadvertently overlooked. This project type should require Regional Centers to partner with CBOs.

Recommendations Workforce Capacity and Development

- Clear guidance should be provided on exactly what cultural competence and linguistic competence mean for individuals (various workforce disciplines including direct support professionals) and organizations (policy and practice). There is not a shared understanding across Regional Centers and CBOs: 1) of what cultural competence and linguistic competence are, 2) of how these practices are defined and conceptualized differently, and 3) that cultural and linguistic are not synonymous with language access. Expanding the available workforce is a long-term goal given the crisis in the number of direct support professionals who have left the service system, particularly after the onset of the COVID-19 pandemic, and for other reasons including wages and working conditions. Consideration should be given to whether or not this area of focus is the most appropriate investment for DDS grant funds.
 - » Collaborate with universities and colleges for practicum experiences with an emphasis on students from the identified racial, ethnic,

and linguistic groups in the legislation.

Consider loan repayment or other incentives for disciplines such as psychology, speech and language pathology, physical therapy, occupational therapy, early intervention, and nursing.

- » Collaborate with communities to increase awareness of the need for respite care providers from underresourced communities and racial, ethnic, and linguistic groups identified by SAE legislation.
- » Collaborate with the State's small business administration to leverage resources and support business ownership from the racial, ethnic, and linguistic groups identified by SAE legislation.

Conduct a national study of successful recruitment and retention of disability professionals (including direct support personnel).

4. Grant measures

- ***Require all projects to report data to show progress and outcomes of activities. Projects should provide both quantitative and qualitative data.***

Quantitative data can be measured, such as the number of participants in Community Connector program, pre/post surveys that are scored with numbers, and comparison of POS expenditures before and after participation in a project.

- More effective measures and evaluation methodologies are needed to document the impact of the SAE Grant Program; DDS or a DDS contractor is needed to provide technical assistance to Regional Centers and CBOs to increase their capacity for effective data collection, analysis, and reporting.
- Include an outcome measurement system based on a DDS logic model and proposed theory of change, for cross-project analysis. This may include changes in awareness and knowledge, increased service use by underserved communities, and improved availability, accessibility, acceptability, quality, and utilization. These data could be collected

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from SAE Grant Program participants first with a baseline survey and then annually and entered by funded projects in a DDS portal.

- Define the minimal data set expected from quantitative outcomes. Comparing POS expenditures before and after participating in a project is dependent upon the nature of the project or project type. There are multiple factors that could affect the expenditures (“n”) for POS.
 - Collect unique client identifiers (UCIs) or similar identifiers to obtain permission from families for data sharing. This would allow outcomes to be tracked in existing data rather than expecting specific types of data collection from the SAE grantees.
 - Focus data collection on meeting the terms of the awards such as the number of people served and a measure of intensity including but not limited to: In what capacity are grantees interacting with persons with IDD and/or with families? How often are grantees interacting with persons with IDD and/or families? How many hours are grantees delivering to persons with IDD and/or their families?
 - Identify and require use of a small number of measures that are appropriate for each project types
- Examine the extent to which the “success stories” gathered for the projects are generalizable to other persons, situations, and settings.
 - Require SAE grantees or an independent entity to conduct focus groups, convene listening sessions, or otherwise query project participants to gather in-depth information regarding whether the Regional Center or CBO improved the availability, accessibility, acceptability, quality, and utilization of supports and services.

A full listing and detailed description of all recommendations for objectives 1-3 and corresponding sub-objectives are presented on pages 58–63 of the narrative report.

Qualitative data is a description, such as what participants say they learned in an orientation and is used to gain an understanding of underlying reasons and motivations and uncover trends in thoughts and opinions. Qualitative data may be collected using open-ended written or verbal questions in surveys, focus groups, and interviews. Findings from qualitative data are typically summarized in writing.

- Link all qualitative data collection and reporting to the DDS logic model and proposed theory of change. Consider amending DDS reporting guidance to require SAE grantees to describe in detail challenges that impeded progress and efforts taken to mitigate challenges and the results.



Final report

Background

In 2016, the California Assembly enacted legislation (AB X2 1) to establish the Service Access and Equity (SAE) Grant Program. This grant program allocated \$11 million dollars to the Department of Developmental Services (DDS) to assist Regional Centers to implement strategies within their respective centers that reduce disparities in purchase of services among the state's racially, ethnically, culturally, and linguistically diverse populations.¹ In fiscal year 2017-2018, this legislation (AB107) was further amended to allow community-based organizations to receive funds from the SAE Grant Program.²

On September 10, 2021, DDS issued a request for proposal to conduct an independent evaluation of

efforts to advance equity and reduce disparities in the state's developmental disabilities services system, specifically focusing on the impact of and future direction for the SAE Grant Program. The Georgetown University National Center for Cultural Competence (NCCC) and Mission Analytics Group partnered to submit a proposal and were awarded a contract on March 11, 2022 to conduct the independent evaluation of the SAE Grant Program. The evaluation was limited to only those Regional Centers and community-based organizations that were funded during fiscal years 2018-2019 and 2019-2020. It is important to note that in FY 2019-2020 California and the entire nation were living through the devastating effects of the COVID-19 pandemic. ***This public health emergency had an adverse impact on the implementation of SAE Grant Programs for FY 2019-2020.***

The California State Legislature and the Department of Developmental Services (DDS) are commended for centering efforts to address racial, ethnic, cultural, and linguistic disparities for persons who experience intellectual and developmental disabilities, their families, the communities in which they live, and the system that provides them with supports and services. The NCCC-MA Team asserts with great confidence that there is no other state nor territory that has enacted legislation and allocated fiscal resources to begin a process to confront and address racial, ethnic, and linguistic disparities in intellectual and developmental disabilities. California leads the nation both in legislation and in allocation of funding toward this end.

Disparities reduction, and corresponding initiatives to address them within DDS are not limited to the SAE Grant Program – nor should they be. One dedicated grant program, even funded at \$11 million dollars annually, simply is not capable of addressing the entrenched and complex array of disparities that disproportionately affect persons who experience intellectual and developmental disabilities and their families from specific racial, ethnic, and linguistic groups. While disparities reduction and equity are related, they are not the same. DDS understands this. The independent evaluation conducted by the NCCC-MA Team documents numerous other efforts within DDS to decrease disparities and advance equity. **Moreover, an analysis of root causes of racial, ethnic, and linguistic disparities within the contexts of intellectual and developmental disabilities services is necessary system-wide, not just within the SAE Grant Program, and should include other California State Departments that deliver services to this population and their contractors and vendors.**

This final report is submitted by Georgetown University National Center for Cultural Competence and the Mission Analytic Group (NCCC-MA Team) to fulfill terms of the contract with DDS. The report includes (a) an executive summary, (b) background, (c) a description of context, (d) assertions, concepts, frameworks, and definitions that underpin the evaluation, (e) Georgetown University Institutional Review Board determinations, (f) listing of project objectives and sub-objectives, (g) evaluation methodology and findings for objectives and sub-objectives, (h) recommendations, (i) references,

and (j) attachments. An extensive appendices is submitted as a separate document.

Context

At the time the request for proposal was issued by DDS, the SAE Grant Program had been implemented for five years, yet it had never been evaluated. Publicly available data from DDS, testimony provided to the California State Senate and Assembly, and widely publicized reports conducted by advocacy organizations and social justice groups document persistent challenges of racial, ethnic, and linguistic disparities that affect persons with lived experience of intellectual and developmental disabilities (IDD) and their families across the state.³⁻⁶ When compared with other states, California has a unique advantage through enacted legislation and a dedicated budget that place high priority on decreasing racial, ethnic, and linguistic disparities among persons with IDD through the SAE Grant Program. It is important to note that DDS leadership and staff are committed to advancing equity within the IDD system, and that the SAE Grant Program *is only one* of many disparities reduction policy and service initiatives implemented by the Department since the grant program was launched.

Disparities based on race, ethnicity, languages spoken (other than English), and geographic locale are the well-documented products of inequities across this nation's human/social services, health and mental health, and education systems.⁷⁻⁹ **Such disparities are not new — neither are they unique to California nor to developmental disabilities systems.** What is unique to developmental disabilities systems nationwide is how they lag far behind in defining exactly what equity means, how equity is manifested in supports and services, how to measure efforts to achieve equity across the complex array of supports and services within these systems, and how to advance equity in partnership with those populations and communities disproportionately impacted by such disparities.¹⁰ This is particularly notable when IDD and public health systems are compared. Public health has a much longer history and focus on racial and ethnic disparities across populations residing in states, territories, and tribal nations. Public health has successfully: (1) defined health equity; (2) created

frameworks to examine the social determinants of health *and* the political determinant of health; (3) established validated measures to document the complexity of racial and ethnic health disparities; (4) developed and implemented evidence-based practices to reduce disparities and promote health equity; and (5) report such findings in multiple ways that are accessible to key constituents, including minoritized communities affected by such disparities.¹¹⁻¹⁴

A review of the extant literature reveals that historical and present-day disparate treatment of persons who experience developmental disabilities based on race, ethnicity, and gender include but are not limited to health care, mental health care, education, housing, employment, childcare, law enforcement, and the justice system.¹⁵⁻³² This literature is largely descriptive and devoid of evidence-based practices focused on disparities reduction. **Most notable is that very little of this literature actually defines equity within the contexts of developmental disabilities in general, and in state-operated systems of supports and services in particular.**



Assertions, conceptual frameworks, definitions, and change theories that underpin the independent evaluation

Georgetown University National Center for Cultural Competence (NCCC) and Mission Analytics Group (NCCC-MA Team) maintain that a comprehensive evaluation of and quality improvement recommendations for the SAE Grant Program required an analysis of not only per capita purchase of service expenditures, but also an examination of the root causes of disparities that affect persons who experience developmental disabilities across racial, ethnic, cultural, and linguistic groups. Commensurate with accepted evidence about disparities and inequities in health and human services, the NCCC-MA Team contends that a comprehensive evaluation must include queries to ascertain the extent to which the following factors contribute to racial, ethnic, and linguistic disparities in California's IDD system: (1) existing policies, regulations, rules, administrative practices, and resource allocation; and (2) socio-cultural, economic, and political environments; and (3) racism, ableism, and other isms. Therefore, the NCCC-MA Team puts forth the following assertions, definitions, conceptual frameworks, and theory of change models that underpin its approach to evaluating the SAE Grant Program.

Assertions

- Disparities are generally regarded as the outcomes of inequities in the policies and system of services and supports in the United States, territories, and tribal nations.³³
- The root causes of disparities that disproportionately affect racial and ethnic populations other than non-Hispanic White are complex and deeply entrenched in the social and structural fabric of this nation.

Root Causes of Inequities

(Adapted from the health equity literature)³⁴

Cluster 1. Root causes of inequities include intrapersonal, interpersonal, institutional, and systemic mechanisms that organize the distribution of power and resources differentially across lines of race, gender, class, sexual orientation, gender expression, disability, and other dimensions of individual and group identity.

Cluster 2. Fundamental root causes of inequities are the unequal allocation of power and resources—including goods, services, and societal attention—which manifest in unequal social, economic, and environmental conditions.

- It must be recognized and accepted that some of the contributing or causal factors for disparities in developmental disabilities supports and services are neither under the auspices nor control of California DDS.
- Persons who experience IDD and their families often require myriad supports and services across multiple systems provided by both the public and private sectors.
- The type and scope of supports and services vary by the structure of the IDD system, allocated resources (fiscal and personnel), and geographic locale.
- Utilization of supports and services by persons with lived experience of IDD and their families is influenced by: age; type of disability; interests and needs; choice; culturally-defined preferences; race and ethnicity; languages spoken other than English, ASL, or other sign languages; experiences of biases, discrimination, marginalization, intersectionality, ableism, racism, and other “isms”; income; insurance/public sector financing; and other factors.
- Understanding the underlying causes and conditions of inequities is essential to informing the complex and effective interventions needed to advance equity in developmental disabilities supports and services.

- Solutions must address the structural causes of disparities in developmental disabilities supports and services that expand beyond emphasis on person-centered services, community outreach and education, multilingual websites, and documents.
- Cultural competence and linguistic competence are proven, evidence-based practices to reduce disparities and promote equity and are underutilized in developmental disabilities systems.
- Commensurate with the cultural competence framework, mitigating disparities and advancing equity are developmental processes that occur over an extended period of time. Outcomes of and metrics for disparity reduction efforts must take this fact into consideration.
- Most state developmental disabilities systems are dependent upon federal legislative authority including policies, regulations, and funding allocations that do not necessarily align with efforts to achieve equity.

Key conceptual frameworks, definitions, and change theories

Cultural competence

In 1989, a work group under the auspices of the Georgetown University Child Development Center published *Toward a Culturally Competent System of Care, Volume 1*. This monograph, by Cross, Bazron, Dennis, and Isaacs, is considered a seminal work and created a conceptual framework and a definition of cultural competence that established a foundation for human services and education. Cultural competence requires that organizations: have a defined set of values and principles, and demonstrate behaviors, attitudes, policies and structures that enable them to work effectively cross-culturally; have the capacity to (1) value diversity, (2) conduct self-assessment, (3) manage the dynamics of difference, (4) acquire and embed cultural knowledge and (5) adapt to diversity and the cultural contexts of the communities they serve; and incorporate the above in all aspects of policy making, administration,

practice, service delivery and systematically involve persons with lived experience, key constituencies, and communities. Cultural competence is a developmental process that evolves over an extended period. Both individuals and organizations are at various levels of awareness, knowledge, and skills along the cultural competence continuum.³⁵

Disparities

As applied to IDD systems, disparities are differences in supports and services given to one person or group when compared to another person or group that cannot be attributed to differences in needs, interests, choice, preferences. This may include and is not limited to disparate treatment, discrimination, bias, insurance, eligibility, accessibility, etc.

Equity

In developmental disabilities equity can be defined as the absence of systematic disparities and unjust systemic policies and practices that unfairly disadvantage persons with developmental disabilities and their families, while unfairly advantaging persons and families without such disabilities, in the pursuit of what is needed to be fully included and valued members of their communities.³⁶

Inclusion

Inclusion has different meanings for different groups of people and fields. There are definitions of inclusion focused on human resource management/staffing, diversity, inclusion, and equity lens, LGBTQI community interests, and from the disability space. While there are many definitions of inclusion the following is used for this evaluation: *Inclusion is active and meaningful engagement, where the inherent worth and dignity of all people are recognized. An inclusive environment promotes and sustains a sense of belonging; it values and practices respect for the abilities, beliefs, backgrounds, and ways of living of its members.*

Inclusion of people with disabilities into everyday activities involves practices and policies designed to identify and remove barriers such as physical, communication, and attitudinal that hamper individuals' ability to have full participation in society,

the same as other people without disabilities. Inclusion involves: (1) Getting fair treatment from others (nondiscrimination); (2) Making products, communications, and the physical environment more usable by as many people as possible (universal design); (3) Modifying items, procedures, or systems to enable people with disabilities to use them to the maximum extent possible (reasonable accommodations); and (4) Eliminating the belief that people with disabilities are unhealthy or less capable of doing things (stigma, stereotypes).³⁷

Life course

“The impact of structural inequities follows individuals from “womb to tomb.” As a concept, life course is defined as a sequence of socially defined events and roles that the individual enacts over time. These events and roles do not necessarily proceed in a given sequence, but rather constitute the sum total of the person's actual experience. In particular, life course directs attention to the powerful connection between individual lives and the historical and socioeconomic context in which these lives unfold. Thus, the concept of life course implies age-differentiated social phenomena distinct from uniform life-cycle stages and the life span. The life course perspective elaborates the importance of time, context, process, and meaning on human development and family life.³⁸

Life course looks at life not as disconnected stages, but an integrated continuum. It is a conceptual framework which recognizes that each stage of life is influenced by the stages that precede it, and in turn influences the life stages that follow it. Life course theory has been adapted to the disability contexts and its components include: 1) a systems change framework consisting of catalysts, leadership and principles, and a set of performance indicators; and 2) the guiding principles of catalysts, infrastructure, innovations, and outcomes.³⁹

Linguistic competence

The following definition, developed by the Georgetown University NCCC is used because it provides a foundation for determining linguistic competence in health care, mental health, education, and other human or social services

systems. Linguistic competence is the capacity of an organization and its personnel to communicate effectively and convey information in a manner that is easily understood by diverse groups including persons of limited English proficiency, those who have low literacy skills or are not literate, individuals with disabilities, and those who are deaf or hard of hearing. Linguistic competency requires organizational and provider capacity to respond effectively to the health and mental health literacy needs of populations served.^{40, 41} The organization must have policies, structures, practices, procedures, and dedicated resources to support this capacity. Moreover, interpretation and translation services must comply with all relevant Federal, state, and local mandates governing language access and similar requirements that ensure access for people with disabilities.

Person-centered

The National Center for Advancing Person-Centered Practices and Systems defines person-centered in three categories. (1) Person-centered thinking focuses on language, values, and actions toward respecting the views of the person and their loved ones. It emphasizes the quality of life, well-being, and informed choice. (2) Person-centered planning is directed by the person with helpers they choose. It is a way to learn about the choices and interests that make up a good life and identify the supports (paid and unpaid) needed to achieve it. (3) Person-centered practices are present when people have the full benefit of community living and supports are designed to assist people as they work toward their desired life goals.⁴²

Self-determination

People with IDD are entitled to opportunities, respectful support, and the authority to exert control in their lives, direct their services, and act on their own behalf.⁴³ The Developmental Disabilities Assistance and Bill of Rights Act of 2000 describes self-determination activities as those activities that result in individuals with developmental disabilities, with appropriate assistance, having: 1) the ability and opportunity to communicate and make personal decisions; 2) the ability and opportunity to communicate choice and exercise control over the type and intensity of services, supports, and other assistance the individual receives; 3) the authority to control resources to obtain needed services, supports and other assistance; 4) opportunities to participate in and contribute to their communities; and) support, including financial support, to advocate for themselves and others, to develop leadership skills, through training in self-advocacy, to participate in coalitions, to educate policymakers, and to play a role in the development of public policies that affect individuals with developmental disabilities.

Theory of change frameworks

Theory of Change is a comprehensive description and illustration of how and why desired change is expected to happen in a particular context. It is focused in particular on mapping out or “filling in” what has been described as the “missing middle” between what a program or change initiative does (its activities or interventions) and how these lead to desired goals being achieved. It does this by first identifying the long-term goals and then works back from there to identify all the conditions (outcomes) that must be in place (and these relate to one another causally) for the goals to occur.^{44, 45} Many efforts to advance diversity, equity, and inclusion do not employ change theories to construct desired outcomes and rely on training (e.g. DEI, implicit bias) as a primary approach to effect deep structural change which is needed within systems.



Disparities: A disability framework

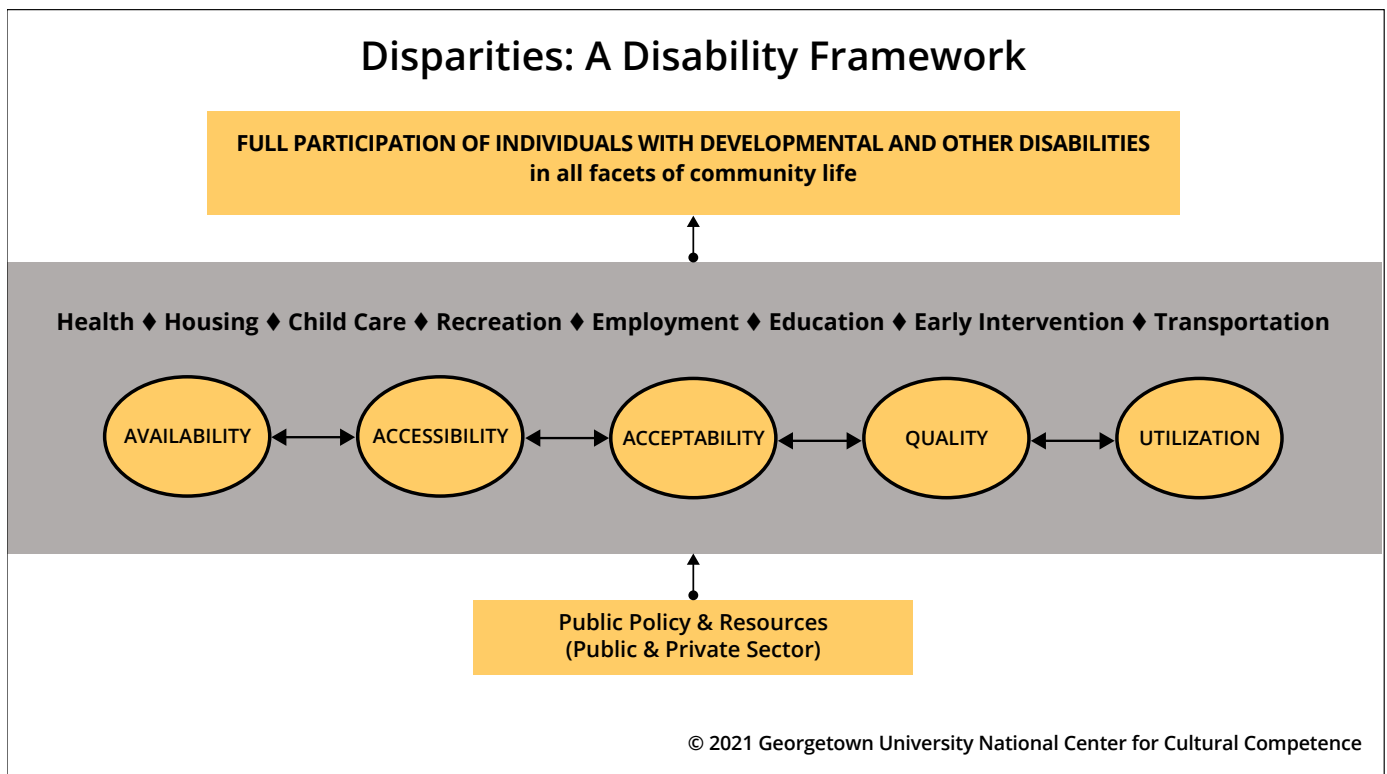
The NCCC-MA Team is using the *NCCC Disabilities Disparities Framework*, (Goode, 2017) depicted in Figure 1, to examine the array of disparities experienced by persons with developmental disabilities and their families who often need supports and services across multiple systems.⁴⁶ The Developmental Disabilities Bill of Rights and Assistance Act of 2000 (DD Act) includes health, housing, child care, recreation, employment, education, early intervention, and transportation. There are other systems which are not delineated in the DD Act in which persons with developmental disabilities are involved such as mental health, social services, judicial, and law enforcement. The NCCC-MA Team used this framework to develop queries that probed – disparities in what?

- **Availability** of supports and services including the array, type, and intensity
- **Accessibility** of supports and services such as geographic distribution, hours of delivery, technology, language access, accommodations, and universal design

- **Acceptability** which principally involves system capacity to plan, deliver, and evaluate culturally and linguistically competent supports and services to diverse populations across the life course
- **Quality** of supports and services across diverse populations and communities. Quality in the context of this framework is defined as the totality of features and characteristics of supports and services that enable systems and organizations to be responsive to and satisfy the interests and needs of a given population
- **Utilization** rates across culturally and linguistically diverse populations including the types of supports and services

It is well documented that resource allocation in both the public and private sectors are contributing factors to disparities. Goode’s Disparities Framework depicts the correlation between the levels of policy and resources, the array of supports and services across multiple systems, and the full participation of persons who experience developmental disabilities in all facets of community life. Each of the three levels are inextricably linked, critical to the evaluation of the SAE Grant Program, and can be applied to the California developmental disabilities system as a whole.

Figure 1. The NCCC Disabilities Disparities Framework



Terms and language used in this final report

This report reflects the NCCC-MA Team's intentional use of language. There are differences in beliefs and practices about person-first or identify-first language related to developmental and other disabilities. The NCCC-MA Team respects each person's right to choose how they self-identify and the terms and language they choose to convey their identity or identities. This final report will use the terms person(s) who experience intellectual and developmental disabilities (IDD), person(s) with lived experience of IDD, population of people with IDD, people or person(s) with IDD, and individual(s) with IDD.

Moreover, identity by race and ethnicity varies significantly in how a person or group self-identifies compared to how data are collected and reported in human service systems. The NCCC-MA Team refrains from using the terms minority or minority populations. When a population is known by race and/or by ethnicity, that designation will be used. California is one of the most racially, ethnically, culturally, and linguistically diverse states in the U.S. and racial and ethnic identities are numerous. California is designated as a "majority minority" state by the U.S. Census which means the state's population is composed of less than 50% non-Hispanic White. The narrative, figures, charts, and tables presented in this report will use the following terms based on data source (i.e., self-identified, administrative data). Refer to Figure 2.

Figure 2. Racial & Ethnic Identities Used in this Report

Race
African American or Black
American Indian or Alaska Native
Asian
Native American
Pacific Islander
White (Hispanic)
White (non-Hispanic)
Other (not specified)
Other — Indian

Other — Mixteco

Other — Two or more races

Unknown

Ethnicity

Hispanic

Hispanic/Latino

Hispanic/Latinx

Non-Hispanic

It should be noted that this report also uses different terms than the language originally specified in request for proposal (RFP) issued by DDS for evaluation of the SAE Grant Program. Specifically, the NCCC-MA team chooses to use the terms *population(s) of focus, focal populations, identified population, and intended or designated audience(s)* instead of "target population(s)" or "targeted group(s) or communities." Many people who are members of and reside in minoritized communities resent and reject "being targeted" even if the underlying intent is positive — to improve service delivery, health and well-being, or aspects of community life. Moreover, the term targeted/target is negatively associated with being a victim, the experience of violence, lack of self-determination, and the capacity to exercise one's own inherent power.

Project objectives and sub-objectives

The NCCC-MA Team proposed the following objectives and sub-objectives in response to the RFP to evaluate the SAE Grant Program. Each of the objectives overlaps and is dependent on: (1) data collection and analyses methods and processes to assess the efficacy of the program; (2) recommendations for quantitative and qualitative measures and metrics based on current evidence, promising practices, change theory models, and other relevant factors; and (3) approaches to prioritize areas of focus, populations, interventions, and modification to the structure of the SAE Grant Program.

Project objective 1

Analyze the impact of the SAE Grant Program using data generated by the grantees and administrative data from DDS to identify changes that would improve the grant program's effectiveness in increasing access and reducing disparities.

- **Sub-objective 1.1.** Characterize the projects and their outputs and outcomes.
- **Sub-objective 1.2.** Measure the impact of these projects on service patterns and expenditures.
- **Sub-objective 1.3.** Use the results of the analysis to identify promising strategies in the grant program.

Project objective 2

Develop qualitative and quantitative measures designed to assess the impacts and outcomes for future SAE Grants administered by California DDS.

- **Sub-objective 2.1.** Recommend quantitative and qualitative outcome/impact measures based on the type and focus of the project and the proven methods that reduce disparities at the individual, family, community, organizational, and systems levels.
- **Sub-objectives 2.2.** Recommend outcome/impact measures are feasible for grantees with different capacities for and expertise in data collection and analysis, different resource levels, and different stages of implementing cultural and linguistic competence at the organization level.

Project objective 3

Develop recommendations for metrics that can be used to prioritize areas of focus, populations, and interventions that will have an impact on disparities reduction at the individual, family, community, organization, and systems levels.

- **Sub-objectives 3.1.** Conduct structured interviews with Regional Centers Directors and SAE Project Managers to elicit information on the implementation and outcomes of their funded programs.*

- **Sub-objectives 3.2.** Conduct small group listening sessions for families to elicit their experiences and insights on disparities and equity within the California IDD system of services and supports.*
- **Sub-objective 3.3.** Conduct structured interviews with staff of the Department of Developmental Services to: 1) review the Department's vision for equity and disparity reduction; 2) elicit their views on the contributing factors to disparities including root causes; 3) ascertain view and evidence of the overall impact of the SAE Grant Program; 4) gauge the Department's willingness and authority to rethink how the SAE Grant Program is structured, administered, and evaluated; and 5) explore the feasibility of changing approaches and components of the SAE Grant Program based on evaluation results and recommendations.*
- **Sub-objective 3.4.** Use Goode's Disability Disparities Framework as a basis for questions to administer a survey for CBOs and conduct listening sessions with Regional Center Cultural Specialists and CBOs that include but are not limited to: 1) describe the role they play in disparity reductions within the California IDD system of supports and services; 2) define equity within the context of IDD supports and services; (3) describe the root causes of racial, ethnic, and linguistic disparities; and (4) describe the role and impact of the SAE Grant Program; and (5) offer recommendations to enhance the SAE Grant Program.*

* During the course of conducting the evaluation, in consultation with DDS, objectives marked with asterisks were modified from the original proposal to engage and elicit experiences of identified constituencies with the SAE Grant Program more effectively.

Evaluation methods and findings

The methodology for the three stated deliverables in the RFP HD219056 and corresponding objectives and sub-objectives that the NCCC-MA Team used to conduct this independent evaluation overlap — each is dependent on data collection and analysis processes to recommend metrics, measures, and priorities for the SAE Grant Program. In order to create and recommend metrics and consistent priorities for the grant program, the NCCC-MA Team relied upon findings of Project Objectives 1-3. Additionally, the overall methodology relied upon the following frameworks and evidence-based literature including:

1. The *NCCC Disability Disparities Framework*;
2. Existing evidence and frameworks to mitigate disparities using proven interventions that focus on the individual, family, community, organizational, and systems levels;
3. The fact that disparities reduction, commensurate with advancing and sustaining cultural and linguistic competence, are developmental processes that occurs over time not in one- or two-year increments based solely on a set of activities; and
4. Reduction efforts must address contributing or root causes of disparities and actively engage populations that are disproportionately affected.

The NCCC-MA Team used mixed methods (quantitative and qualitative) to evaluate the SAE Grant Program. The following narrative details the methodology and findings for the three objectives and their corresponding sub-objectives.

Objective 1

Analyze the impact of the SAE Grant Program using data generated by the grantees and administrative data from DDS to identify changes that would improve the grant program's effectiveness in increasing access and reducing disparities.

- **Sub-objective 1.1.** Characterize the projects and their outputs and outcomes.

Methods

To address objective 1, the quantitative analysis examined changes in disparities between 2017/18 and 2021/22 for five outcomes that can be matched to the work of the SAE projects.

These include:

- The likelihood that young children from communities of color are assessed for Early Start services,
- The share of DDS individuals using any paid services and the expenditures on services other than residential care, and
- The share of DDS individuals using respite care and the expenditures on respite care services.

The analysis combined data from three sources: (1) Grant program data submitted by SAE projects as part of the administration of the SAE Grants, including evaluator coding of grant narratives; (2) administrative data from DDS including the client master file (CMF) and purchase of service (POS) data from 2017 to 2022; and (3) Department of Finance population estimates by county and age from 2017 to 2022.

The analysis focused on SAE projects with project goals or outcomes tied to one of the outcomes listed above. The included projects were further narrowed to projects where the population of focus could be identified in administrative data with sufficient data for analysis. Because data was not available to indicate the individuals directly served by the SAE projects, the analysis tracked changes for all individuals from the focal population at the Regional Center served by the project.

The projects included in the impact analysis focus on communities of color as selected by the grantees

and identifiable in the administrative data by race or ethnicity. Each group's gains were calculated, but a comparison group was needed to account for the rapid changes in the DDS population and POS expenditures over the period. Non-Hispanic White individuals were selected as the comparison group for two reasons. First, they were not the focal group for the projects in the analysis. Second, the SAE program was motivated by "studies ...[that] consistently find that communities of color are less likely to receive Regional Center services, and receive lower than average (per capita) POS, compared to individuals who identify as White."¹

Outcomes for the focal groups were compared to those for non-Hispanic White individuals to understand whether gains (or losses) for the project populations reflected reductions in disparities over time. However, in the context of Culturally Responsive and Equitable Evaluation (CREE), comparisons such as those here should be considered with caution. As a leader in the field describes,

While we do need a comparison group, we also need to be explicit about the structural factors and root causes that may have led to disparities. Taking a CREE approach is not just about identifying disparities as it compares to another race, but also includes a focus on the root causes and the solutions needed (while centering those most impacted). K. Andrews (personal communication, August 28, 2023).

For example, expenditures for non-Hispanic White individuals should not be considered a norm or benchmark.

For all projects, non-Hispanic White individuals in the same Regional Center and age group were the comparison group. Regional Centers often had multiple projects serving the same SAE populations, so changes could not be attributed to specific projects.

SAE Project Characteristics

The quantitative analysis focused on 54 SAE projects out of 101 projects from 2018/19 and 2019/20, based on their objectives and populations of focus. As shown in Table 1 more than half of these projects (28) listed the objective of increasing Early Start assessments for children from their focal communities. The remaining projects cited objectives of increasing POS generally (17 projects) or respite care specifically (9 projects). Among the 54 projects, 34 were led by CBOs and 20 were led by Regional Centers.

Projects concentrating on Early Start assessment served more than 125,000 people. Projects with family support, Promotora, or outreach as their primary type served most of these people, with 20 of the 28 projects including substantial outreach services. The projects that concentrated on increasing POS or respite care served a smaller number of people, 11,734 and 5,287 respectively, but a larger share of people served by these projects received Promotora services.

The analysis calculated changes in disparities for the focal groups served by these projects. Since the persons served were not identified in the data, the changes were calculated for all individuals from the SAE focal groups in the Regional Centers served by these projects. There were 75 combinations of Regional Center-race/ethnicity groups that were the focus of the 54 SAE projects (Table 2). Hispanic individuals were the most common focus of the SAE projects, including Early Start assessment projects in 16 Regional Centers, POS-focused projects in 16 Regional Centers, and respite care-focused projects in 4 Regional Centers. Native American children were the focal population for SAE projects focused on Early Start assessment at two Regional Centers. None of the POS-focused projects included in the analysis focused on Native American populations.

1 ^{**} <https://www.dds.ca.gov/rc/disparities/disparity-funds-program/grant-structure/>

Table 1: Characteristics of SAE Projects in Quantitative Analysis, By Project Objective and Primary Project Type

Primary Project Type	Family Support	Outreach	Parent Education/ Training	Promotora	Translation	Workforce Capacity	Total
Example Activities	1:1 coaching, enhanced case mgt, service navigation	community events, outreach	online or in person trainings, workshops	peers educating community members on accessing RC services	equipment, translator services, translating brochures or materials	staff training, incentives for bilingual employees	
Projects Mapped to Goal of							
Early Start Assessments	4	9	4	7	1	2	28
Increased POS	2	3	3	8	-	1	17
Increased Use of Respite	2	2	-	2	2	1	9
People Served, By Goal							
Early Start Assessments	46,245	31,690	578	45,864	-	872	125,249
Increased POS	205	2,877	-	7,809	-	843	11,734
Increased Use of Respite	-	811	-	3,835	641	-	5,287

Table 2: Race/Ethnicity Focal Groups for SAE Projects in Quantitative Analysis, By Project Objective

Regional Centers with SAE Projects Focused on ¹	Early Start Assessment	Increased POS	Increased Respite
Asian/Pacific Islander	10	6	3
Black/African American	9	7	2
Hispanic	16	16	4
Native American	2	0	0
Total	37	29	9

SAE projects focusing on multiple groups (e.g. Black and Native American children) are counted under each. Regional centers with multiple SAE projects addressing the same group and outcome (e.g. two projects working to increase POS in the same regional center) are counted only once. ²Includes projects focused on specific communities such as Hmong.

Analysis of administrative data

Regional Center-SAE focal groups had increased likelihood of early start assessment

Twenty-eight of the SAE projects in the analysis sought to reduce disparities in assessment for Early Start services, through activities such as encouraging families to have their children screened and supporting families who bring their children for assessment.

Since Regional Center catchment areas differ in demographic makeup, the evaluation first calculated likelihood of children 0-3 being evaluated for services in each California county, measured as the number of children evaluated for every 10,000 children from a focal race/ethnicity group residing in the county. For example, statewide, 1,450 Asian/Pacific Islander children aged 0-3 were evaluated for every 10,000 Asian/Pacific Islander children in this age bracket. This rose to 2,106 out of every 10,000 in 2021/22, a 45% increase in the likelihood of an Asian/Pacific Islander child being assessed for Early Start.

Between 2017/18 and 2021/22, the likelihood of children being assessed for Early Start rose for all major race/ethnicity groups captured in annual county population data. To assess the change in disparities in assessments, the question is whether

the likelihood of assessment grew faster for children from the SAE focal populations. As a comparison group, the evaluation calculated how much more (or less) likely non-Hispanic White children were to be assessed in the same Regional Centers.

Figure 3 shows the relative likelihood being evaluated for Early Start services for SAE focal populations compared to non-White Hispanic children. In the Regional Centers served by the SAE projects, children from the focal race/ethnicity groups on average were 49% more likely than non-White Hispanic children to be evaluated for Early Start in 2017/18. After the service periods for the SAE projects, this difference had more than doubled. In 2021/22, children from the SAE focal groups were more than twice as likely to be evaluated for Early Start services compared to non-White Hispanic children in the same Regional Center counties.

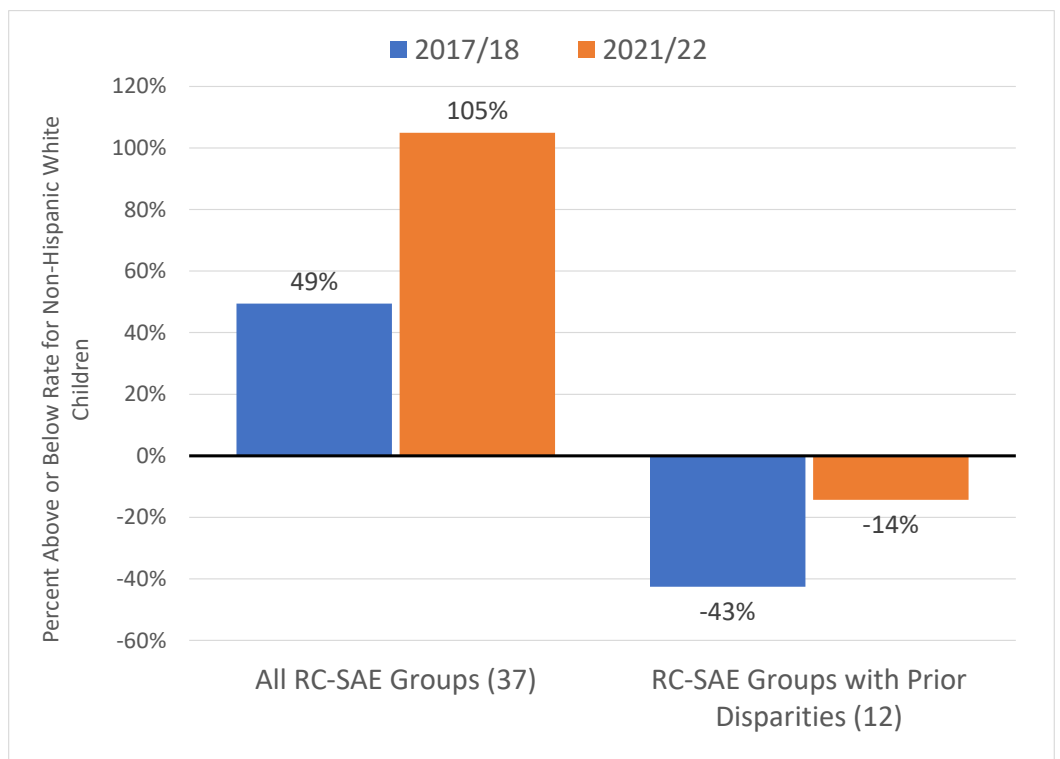
In fact, out of 37 Regional Center-SAE focal groups, only 12 groups were less likely to be evaluated for Early Start in 2017/18. On average, children from these groups were 45% less likely to be assessed for Early Start than their non-White Hispanic counterparts. Looking in 2021/22, after the SAE projects, the disparities for these groups were lessened but not erased. Children from groups that had prior disparities in the likelihood of being assessed were, on average, 14% less likely than non-Hispanic White children to be assessed for Early

Start in 2021/22. Native American families were the only SAE focal groups that did not achieve gains in assessments relative to non-Hispanic White children.

The changes shown in Figure 3 were observed for the SAE groups at the Regional Center level and cannot be specifically attributed to the SAE projects. In the years studied, Regional Centers and DDS were working more broadly to address disparities. Multiple SAE projects were funded at the same time or in succession at the Regional Centers, including projects before and after those examined in this evaluation. Even for the projects in the analysis, the focal group can be identified but not the individuals served by the SAE projects.

The analysis also looked at different characteristics of SAE projects to assess their impact on the magnitude of these changes. Regional Center groups served by projects that started before June 2018 experienced bigger gains than groups from more recent projects. Some of the projects were continuations or adaptations of earlier projects, with start dates in 2017 and sometimes earlier. These projects not only ran longer but also had more time for gains to accrue. Gains were also larger where projects reported successes that generalize to broad populations or where outcomes reported by the project indicated decreases in at least one type of disparity.

Figure 3. Relative Likelihood of Children Under 3 Being Evaluated for DDS Services, Regional Center-SAE Groups Compared to Non-Hispanic White Children



Regional Center-SAE focal groups had increased purchase of services

To assess the effect of the SAE projects on disparities in purchase of service (POS), the evaluation looked separately at the likelihood of having any POS and the average POS expenditures among individuals with any POS. Because the SAE projects considered did not seek to increase residential services, individuals receiving residential services were excluded from the calculations of average POS expenditures.^{***2}

As shown in Figure 4, in the Regional Centers with SAE projects focused on increasing POS, the SAE focal groups were only slightly less likely than non-Hispanic White individuals to have any POS expenditures in 2017/18. In the Regional Centers with projects focused on these groups, Asian and Black individuals were about 3% less likely than non-Hispanic White individuals to have any POS, and Hispanic individuals were about 2% more likely to have any POS. Adults aged 22 and older from the SAE focal groups were less likely to have any POS

compared to their non-Hispanic White counterparts, with an average 9% lower likelihood of having POS expenditures in 2017/18.

In 2017/18, there were larger disparities in the average POS expenditures for the Regional Center-SAE groups. Averaged across the SAE groups, POS expenditures were 14.5% lower for the focal populations than for non-Hispanic White individuals in the same age groups and Regional Centers. These 2017/18 disparities were common across most age and race/ethnicity groups that were the focus of the SAE projects, with adults having the largest disparities in expenditures compared to non-White Hispanics.

By 2021/22, the Regional Center-SAE groups had increases in both the shares with any POS and in average POS expenditures. The increase in the shares with any POS resulted in the SAE groups being 2% more likely to have POS expenditures compared to non-White Hispanic individuals in their Regional Centers. There were improvements for all age groups. However, disparities remained for adults from the SAE groups. In 2021/22, adults aged 22 to 59 years old were 7% less likely to have any POS expenditures than non-Hispanic White adults in their Regional Centers.

The gains were larger for average POS expenditures, although disparities remained. In 2021/22, on

2 ***Adults 21 to 59 years old are the most likely to have residential care, but only 18 percent of individuals in this age group used residential care (such as community care facilities) in 2021/22. POS expenditures are much higher on average for individuals with residential care.

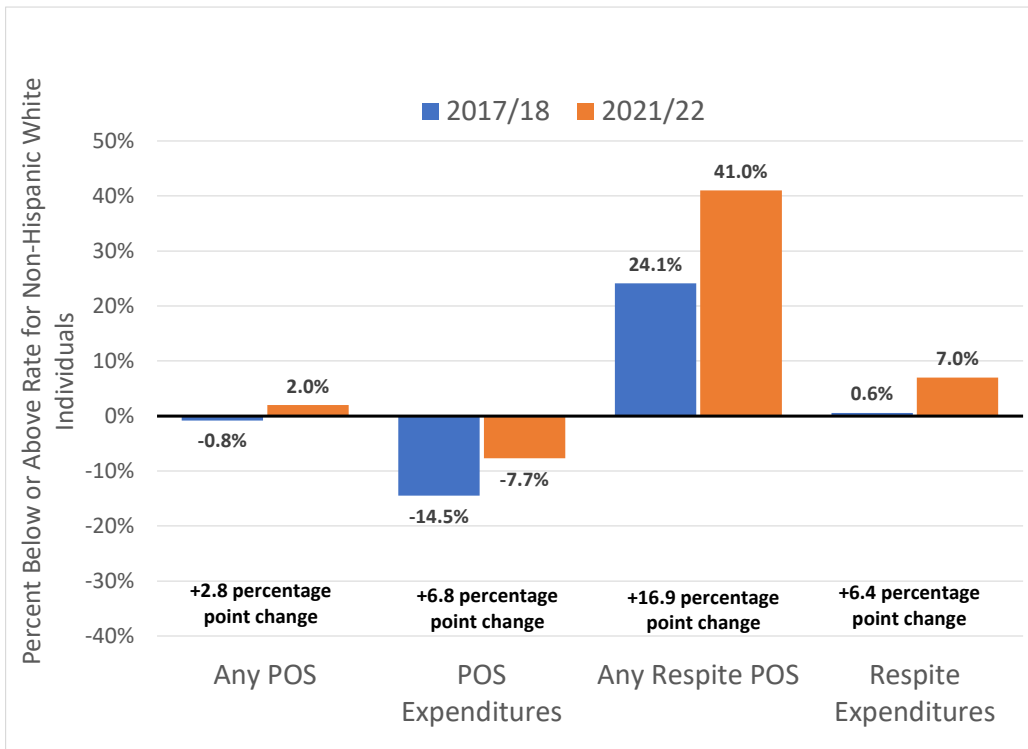


Figure 4: Relative Likelihood of Having Any POS and Average POS Expenditure, Regional Center-SAE Groups Compared to Non-Hispanic White Individuals

average, POS expenditures for the SAE groups were 7.7% below expenditures for non-Hispanic Whites in the same age groups at the same Regional Centers. This represented a 6.8 percentage point reduction in disparities. Most age and race/ethnicity groups that were the focus of SAE projects had POS expenditures rise faster than expenditures for non-White Hispanic. The largest improvement occurred for children aged 4-15 years old. Adults from SAE groups made the smallest gains. In 2021/22, their POS expenditures were 30% below those for non-White Hispanic adults.

The analysis also examined SAE project features associated with larger impacts on POS. The same caveat applies to these outcomes as with the Early Start assessments: Changes observed at the Regional Center level cannot be specifically attributed to the SAE projects. However, Regional Centers with SAE projects that were primarily Promotora had among the highest percentage point gains for reducing disparities in receiving any POS and the amount of POS. Regional Centers where there were SAE projects focused on parent education and training projects also had strong improvements on POS expenditures, though the impact on the shares with any POS were smaller. Similarly, Regional Center-SAE groups had similar outcomes for shares with any POS if projects were led by CBOs or by the Regional Centers. Regional Centers that led projects showed greater changes on the POS expenditures, perhaps reflecting the greater control of Regional Centers over POS expenditures, where CBOs may necessarily focus more on education, advocacy, and navigation. The higher relative gains for Regional Center-led projects may also reflect the fact that Regional Center projects were running longer. As with the Early Start projects, longer term projects focused on POS were associated with larger relative gains.

Regional Center-SAE focal groups had increased use of respite care

Figure 4 also shows parallel results for the nine Regional Center-SAE groups where projects focused on increasing respite care. On average, the groups that were the focus of these projects were 24.1% more likely than non-Hispanic White individuals

to receive respite care before the projects. This average hides some differences between groups: Asian groups that were the focus of these projects were less likely than non-White Hispanic individuals to receive respite care in 2017/18. Children aged 4 to 15 years old from the SAE groups were also less likely to receive respite care.

Among those receiving any respite care, 2017/18 respite care expenditures for the SAE groups were almost identical to non-Hispanic White individuals in the same age groups and Regional Centers. Again, there were differences among the SAE groups. Among those with any respite care, Black individuals had lower average respite care expenditures than non-White Hispanic individuals in the same age brackets. Adults from the SAE groups had lower average respite care expenditures than non-White Hispanic adults, with the largest disparities for Black adults in the Regional Centers with SAE projects focused on respite.

By 2021/22, the SAE groups for projects focused on respite care had greater shares with any respite care and greater expenditures on respite care. Overall, individuals from the SAE groups were 41% more likely to have any respite care compared to non-Hispanic White individuals in the same age brackets at their Regional Centers. Accounting for age groups, respite care expenditures rose faster for the SAE groups than for their non-Hispanic White counterparts. In 2021/22, average respite expenditures were 7% higher for the SAE groups than for non-Hispanic White individuals of the same age.

All age and SAE race/ethnicity groups had larger shares of individuals receiving respite care through the Regional Centers with SAE projects focused on this outcome. Between 2017/18 and 2021/22 disparities in the share with any respite care were eliminated for children aged 4 to 15 years old from the Asian populations of focus for the SAE projects. Disparities remained for individuals aged 16 and older from these Asian communities, although the differences relative to non-Hispanic White individuals were cut in half.

The rise in the share of individuals with any respite care appeared to reduce the average respite care expenditures for some groups, even as the average effect was positive overall. Disparities in respite care

expenditures were erased for Black youth aged 16 to 21 years old, but worsened somewhat for Black adults. Regional Centers with projects focused on Black adults saw the largest gain in the share of persons with any respite care. Overall adults from the SAE groups continued to have lower average respite care expenditures than non-Hispanic adults in their Regional Centers, but the disparity was smaller in 2021/22 than four years earlier.

Due to the small number of Regional Centers with respite care projects, and the overlap in the number of projects in the same Regional Centers, there was not sufficient data to assess the relationship between observed project characteristics and reduced disparities in receipt of any respite care and the amount of respite POS.

Summary of findings

Key findings from the quantitative analysis conducted for Objective 1 informed recommendations for metrics that can be used to prioritize areas of focus, populations, and interventions that impact disparities reduction (Objectives 2 and 3).

1. 54 of the 101 SAE projects funded in 2018/19 and 2019/20 had project objectives that mapped to increased Early Start assessments, POS expenditures, or respite care expenditures and also had focal populations that could be identified in administrative data.
2. These 54 projects reported serving more than 142,000 individuals, representing 75 combinations of Regional Centers and race/ethnicity groups. Promotora Projects represented the largest share of these projects, followed by outreach projects, which were most likely to focus on Early Start assessment.
3. By 2021/22, children from SAE focal groups in Regional Centers where SAE projects focused on Early Start assessment were more than twice as likely to be assessed for Early Start compared to non-Hispanic White children from the same Regional Centers (controlling for population sizes). Only a third of the SAE projects were focused on groups that were less likely to be assessed as of 2017/18. For those groups, disparities relative to non-Hispanic White children were reduced but not eliminated.

4. In Regional Centers where SAE projects focused on increasing POS expenditures (other than for residential care), the share of individuals with any POS expenditures increased more between 2017/18 and 2021/22 for SAE focal groups compared to non-Hispanic White individuals in the same age brackets.
5. Average POS expenditures also increased more for SAE focal groups, but the increases were not large enough to eliminate the disparities in POS expenditures. By age category, disparities were largest for adults from the SAE focal groups.
6. Between 2017/18 and 2021/22, both the share of individuals with respite care and the average respite care expenditures rose faster for SAE groups than for non-Hispanic White individuals in Regional Centers where SAE projects focused on increasing respite care.
7. Changes were larger in Regional Centers where SAE projects had been in place the longest.

Objective 2

Develop qualitative and quantitative measures designed to assess the impacts and outcomes for future SAE Grants administered by California DDS.

Methods

As previously stated, the methodological approach for the three project objectives put forth by the NCCC-MA Team overlap and cannot be conducted in the sequential order of deliverables listed in the RFP issued by for evaluation of the DDS Service Access and Equity. To address objective 2, the NCCC-MA team conducted a mixed methods analysis of the SAE Grant Program. *Recommendations for this objective and all objectives are combined in one section on pages 58–63 of this report.*

- **Sub-objective 2.1:** Recommend quantitative and qualitative outcome/impact measures based on the type and focus of the project and the proven methods that reduce disparities at the individual, family, community, organizational, and systems levels.

The methodology for sub-objectives 2.1 consists of the following:

- Review and interpret the current array of metrics developed by DDS to determine the extent to which they are effective measures of disparity reduction.
- Explore and document how funded projects advance and define equity.
- Draw upon measures from *Cultural and Linguistic Competence Policy Assessment*, *Cultural and Linguistic Competency Assessment for Disability Organizations*, and other measurements for disparity reductions and equity advancement.

Approach justification

Given that one of the purposes of this evaluation is to recommend changes that would improve the SAE Grant Program's effectiveness to increase access and reduce disparities for persons with lived experience of IDD and their families, it is paramount that the voices of diverse communities are included in the collection and interpretation of data. The methodology employed by the NCCC-MA Team used tenets of culturally responsive and equitable evaluation (CREE).⁴⁷ Tenets of CREE consider contextual dimensions, such as demographic, sociopolitical status, location, and community perspectives and characteristics as a foundation of the evaluative process. Otherwise, the diversity of perspectives is ignored which contributes to the underrepresentation, misrepresentation, and distortion of communities and their information.⁴⁸

Developing measures to evaluate the effectiveness of a multifaceted IDD system of supports and services require adhering to well-established principles and practices of community engagement. For the purposes of this evaluation, the NCCC-MA Team defined community engagement as follows.

“Community engagement is the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people or populations. It is a powerful vehicle for bringing about changes that will improve the well-being of communities and their members by equalizing power and advancing equity. It involves partnerships and coalitions that help mobilize resources and influence systems, change relationships among service providers and community members, and serve as a catalyst for changing policies, programs, and practices.”⁴⁹

Findings: Sub-objective 2.1

- ***DDS measures used to assess disparities reduction within the SAE Grant Program***

DDS submitted a written document on 2/27/23 in response to queries (listed below) regarding existing measures used to assess the impacts and outcomes of the SAE Grant Program. The following responses were factored into the overall analysis and informed recommended qualitative and quantitative measures based on current evidence-based and promising practices in disparities reduction that can be adapted and applied to developmental disabilities.

- ***Does DDS have different measures or criteria to assess the extent to which the SAE grantee program reduced disparities based on categories (i.e., translation, outreach, workforce capacity, parent education, Promotora, family/person with lived experience supports and services)?***

DDS did not have grant-wide program measures to assess the impact of the SAE Grant Program on disparities reduction for the 2018-19 and 2019-20 grant cycles. It is important to note that DDS does currently provide [guidance](#) on how to report data that show progress and outcomes of grant activities in the 2023-2024 grant cycle.

The aforementioned guidelines offer potential applicants and grantee recipients detailed instructions and definitions on quantitative and qualitative data, developing project objectives, and creating appropriate measures that are project related. Additionally, guidance is provided for Grant Vantage Measure categories including number, milestone, percentage, percentage increase in purchase of services (POS), and narrative. Refer to Chart 1 on page 40 for examples of specific outcome and impact data collected by grantees submitted by DDS on 2/27/23. However, the focus of the grant categories that were funded during FY 2018-2019 and 2019-2020 (i.e., translation, advocacy, parent

training and engagement) do not consistently show a direct correlation and measurable impact on disparities reduction, with the exception of the Promotora and Enhanced Case Management grants. DDS reported that there is limited capacity among: (1) grantees (Regional Centers and CBOs) to collect and analyze the types of data that demonstrate impact on disparities reduction; and (2) SAE Division staff to provide the technical assistance and monitoring necessary to increase grantee performance due to limitations in staff size and multiple responsibilities. It is important to note that data collected from Regional Centers and CBOs for Project Objective 3, are consistent with (1) above as reported by DDS.

Chart 1. Submitted by DDS on 2/27/23. Examples of Project-Specific Outcome or Impact Data Collected by Grantees (This is not an exhaustive list.)

Project type	Type of outcome or impact data collected
Promotora	Pre/Post Purchase of service
	Standardized Survey assessing knowledge gain, empowerment, and satisfaction with connector service (20-21 began collection)
	Pre/post Barriers experienced by participants (20-21 began collection)
	Pre/post RC and Generic Services acquired (20-21 began collection)
Family Supports	POS before/after
Parent Education (Very Difficult to Directly Assess Impact)	Pre/post knowledge Satisfaction Surveys Quality of Life Survey Parent comments
Outreach (Very Difficult to Directly Assess Impact)	Success Stories Family Comments about developed resources (e.g., videos) Reach of videos (e.g., views)
Translation (Very Difficult to Directly Assess Impact)	Success Stories Family Comments about usefulness of interpretation or translation Number of people viewing or downloading translated documents electronically, accessing interpretation, etc.
Workforce (Very Difficult to Directly Assess Impact)	Number of people served by the new bilingual hires Pre/post knowledge gain in cultural competency trainings

- **Does DDS have specific measures or criteria to assess the extent to which the SAE grantee program increased access for persons who experience IDD (across the lifespan) and their families?**

DDS reported that there are no current lifespan measures to determine the extent to which the SAE Grant Program increases access to persons who experience IDD across the lifespan. However, DDS is open to exploring opportunities to assess potential lifespan measures.

- **Is there one set of measures or criteria across all SAE grantee programs to assess disparities reduction and/or increased access?**

DDS reported that there is no one set of measures and criteria across the SAE Grant Program for disparities reduction.

- **Is there a logic model that DDS uses for disparities reduction in the SAE Grant Program (if so, please share).**

DDS reported that it neither uses a logic model nor requires grantees to use a logic model to advance equity and reduce disparities in the implementation of the SAE Grant Program.

In conclusion, the grant categories that were funded during FY 2018-2019 and 2019-2020 (i.e., translation, advocacy, parent training and engagement) do not consistently show a direct correlation and measurable impact on disparities reduction, with the exception of the Promotora and Enhanced Case Management grants. DDS reported that there is limited capacity among: (1) grantees (Regional Centers and CBOs) to collect and analyze the types of data that demonstrate impact on disparities reduction; and (2) SAE Division staff to provide the technical assistance and monitoring necessary to increase grantee performance due to limitations in staff size and multiple responsibilities. It is important to note that data collected from Regional Centers and CBOs for Project Objective 3 are consistent with (1) above as reported by DDS.

- **Ascertain how SAE Grant projects define and advance equity**

The Regional Centers and CBOs reported that DDS neither provided an official definition of equity nor a blueprint and guidance to advance the concept and practices of equity within the SAE Grant Program. Additional findings from the interviews and surveys with Regional Centers and CBOs are reported in Objective 3.

Methods

- **Sub-objectives 2.2:** Recommend outcome/impact measures are feasible for grantees with different capacities for and expertise in data collection and analysis, different resource levels, and different stages of implementing cultural and linguistic competence at the organization level.

To accomplish objective 2.2., the NCCC-MA Team included queries in the structured interviews, survey, and listening sessions for Regional Centers and CBOs to ascertain: (1) Their capacity for data collection and analysis; (2) The associated cost burden for staffing and software platforms; (3) What types of technical assistance and consultation will be needed if the current measures and data collection processes are amended; and (4) Recommendations for measures that reflect their experience implementing the Service Access and Equity grant program. The methodology also relied upon the following frameworks and evidence-based principles and practices previously described on pages 60–20 of this report: (a) The *NCCC Disability Disparities Framework*; (b) Existing evidence and frameworks to mitigate disparities using proven interventions that focus on the individual, family, community, organizational, and systems levels; (c) The fact that disparities reduction, commensurate with advancing and sustaining cultural and linguistic competence, are developmental processes that occurs over time not in one- or two-year increments based solely on a set of activities; and (d) Reduction efforts must address contributing or root causes of disparities and actively engage populations that are disproportionately affected.

Approach justification

Cultural competence and linguistic competence are proven evidence-based practices for reducing disparities. Therefore, NCCC-MA Team relied upon the cultural competence framework that asserts: Cultural competence is a developmental process that evolves over an extended period. Both individuals and organizations are at various levels of awareness, knowledge, and skills along the cultural competence continuum. This principle can be similarly applied to disparities reduction. **Organizations and agencies in the California IDD system of supports and services are at various stages and capacities in their efforts to mitigate disparities and advance equity. Since IDD service providing organizations are not similarly situated, measures will need to allow for this developmental progression — in other words one size does not fit all.** Measures are needed that: (1) are user-friendly; (2) do not require external evaluation expertise to implement; (3) are not dependent upon large human or financial resources and investments; (4) can easily align with where organizations are in terms of implementing cultural and linguistic competence; and (5) correlate with the State of California's goals for achieving equity. Measures will need to be constructed in a manner that address the individual, family, community, organizational, and systems levels of IDD supports and services in California since disparities manifest at each of these levels.

Further, it is important to recognize that measures for disparities reduction and advancing equity serve a common purpose but they are not the same. Disparities are the product or outcomes of inequities. Therefore, measures will need to be differentiated based on a shared understanding and acceptance of definitions of disparities and equity — and specific theories of change for decreasing one (disparities) while simultaneously advancing the other (equity). The NCCC-MA Team considered the findings of Objectives 1 and 3 to in order to develop and recommend a set of measurements that are responsive to the complex system of supports and services and the demographic makeup of the IDD population in California. *Recommendations for this sub-objective and all objectives are combined in one section on pages 79-85 of this report.*

Objective 3

Develop recommendations for metrics that can be used to prioritize areas of focus, populations, and interventions that will have an impact on disparities reduction at the individual, family, community, organization, and systems levels.

Methods

To address objective 3 and sub-objectives 3.1–3.4, the NCCC-MA Team employed mixed methods to identify, collect, and analyze data consisting of:

- Individual structured interviews with Regional Center Directors and SAE Project Managers (conducted virtually). The interview questions are located in Attachment A.
- Individual structured interviews with DDS staff (conducted virtually) representing different levels and responsibilities for the SAE Grant Program within the Department. The questions are located in Attachment B.
- Virtual listening sessions designed for Cultural Specialists employed by the 21 Regional Centers in the state. Questions are located in Attachment C.
- Virtual listening sessions with CBOs that received SAE Grants. Questions are located in Attachment D.
- A survey administered to CBOs that received SAE Grants. The survey instrument is located in Attachment E.
- Virtual listening sessions for families of persons who experience IDD, across the life span, who participated in the SAE Grant Programs and families who self-registered to participate. Questions are located in Attachment F.

Georgetown University Institutional Review Board

This evaluation was granted exemption on August 15, 2022, by the Georgetown University Institutional Review Board (IRB) after review of the protocols and related supporting materials. Categories of exempt research are stipulated in Federal regulations at 45 CFR 46.101 (b)(1-6) and include: Research and demonstration projects which are conducted by or subject to the approval of department or agency

heads, and which are designed to study, evaluate, or otherwise examine public benefit or service programs.

The initial exemption by the Georgetown University Institutional Review Board covered the following activities:

- Structured interviews with Regional Center Directors
- Structured interviews with SAE Project Managers
- Structured interviews with DDS staff
- Listening session for Cultural Specialists and CBO staff
- A survey of CBO staff

An amendment was submitted to Georgetown University IRB for the listening sessions with family members of persons with intellectual and developmental disabilities. It was approved on December 20, 2022.

Approach justification

As previously stated, the methodological approach for the three project objectives put forth by the NCCC-MA Team overlap and cannot be conducted in the sequential order of deliverables listed in DDS Service Access and Equity RFP. In order to create and recommend metrics and consistent priorities for the grant program, the NCCC-MA Team relied upon data analysis findings gleaned across project objectives. The methodology also relied upon the following frameworks and evidence-based principles and practices previously described on pages 20-23 of this report: (a) The *NCCC Disability Disparities Framework*; (b) Existing evidence and frameworks to mitigate disparities using proven interventions that focus on the individual, family, community, organizational, and systems levels; (c) The fact that disparities reduction, commensurate with advancing and sustaining cultural and linguistic competence, are developmental processes that occurs over time not in one- or two-year increments based solely on a set of activities; and (d) Reduction efforts must address contributing or root causes of disparities and actively engage populations that are disproportionately affected.

- **Sub-objectives 3.1.** Conduct structured interviews with Regional Center Directors and SAE Project Managers to elicit information on the implementation and outcomes of their funded programs.*

Methods

- The NCCC used Goode's *Disability Disparities Framework* and developed interview questions designed to probe the extent to which Regional Centers: 1) defined disparities and their underlying causes; 2) described how their SAE Grant projects were designed to mitigate disparities at the individual, family, community, organizational, or systems levels; 3) used theory of change theories/frameworks to reduce disparities at multiple levels;
- 4) provided evidence that their SAE Grant projects actually reduced disparities (not solely limited to per capita purchase of services expenditures); 5) identified measures that verified/demonstrated reductions in disparities among specific populations; 6) employed cultural and linguistic competence in supports, services, project activities and allocated fiscal resources for this capacity; 7) engaged persons with lived experience and/or their families to evaluate supports and services received; 8) collected and analyzed data on project findings by race, ethnicity, languages spoken, SES, geographic locale, and other factors; 9) analyzed the effect of funding on their capacity to increase access; 10) defined equity in IDD supports, services, and related activities; and 11) employed a logic model to demonstrate the correlation between advancing equity and disparities reduction within their SAE Grant projects. Regional Center Directors and SAE Project Managers were also asked to identify specific quality improvement recommendations they have for the SAE Grant Program.

Regional Center directors and SAE project managers interviews

Conducting interviews with Regional Center Directors and SAE Project Managers about their SAE Grant Programs was an important component of the overall evaluation design. The Regional Center Directors and SAE Project Managers were responsive, prepared, and engaged in the

evaluation process. A structured interview protocol was developed by the MA-NCCC Team, reviewed internally by all project faculty, staff, and the Georgetown University Institutional Review Board. Additionally, the interview protocol was shared with DDS. The final interview protocol provided the Regional Center Directors and the SAE Project Managers with an overview, purpose of the interview process to elicit information related to their SAE Grant projects funded during FY 2018-2019 and FY 2019-2020, a copy of the interview questions, and information on informed consent. Interviews were conducted virtually and completed with Regional Center Directors and SAE Project Managers in all but eight Regional Centers. In total 34 people were interviewed (18 Regional Center Directors and 16 SAE Project Managers). It should be noted that some SAE Project Managers served dual roles as Regional Center Cultural Specialists.

The sample size for the structured interviews consisted of 21 Regional Center Directors and 21 SAE Project Managers. Participants were contacted via email by members of the NCCC-MA Team to schedule an interview. The NCCC-MA Team set up a Google booking link for participants to select a date and a one-hour timeslot. Participants were given a Google forms link to an informed consent form with instructions to review it and to provide their electronic consent agreeing to participate at least 48 hours prior to their scheduled interview. If Regional Center Directors and SAE Project Managers did not respond, reminder emails were sent, including the previously cited links.

Web conferencing details were sent to participants after confirmation, including a copy of the structured interview questions. Refer to Attachment A. The interviews were conducted virtually on Zoom™ with designated NCCC-MA Team. The interviews were scheduled for approximately 60 minutes. At the start of the interview, the interviewer provided a brief overview of the evaluation and reminded participants that the session would be audio and video-recorded, as stated in the informed consent document. The structured interviews were then transcribed and prepared for analysis.

Data collection and analysis

As stated above, a total of 34 structured interviews were completed from October 28, 2022 – March

07, 2023. The majority of participants (n = 31) were interviewed during the months of October – December 2022. However, due to scheduling conflicts, the remaining participants (n = 3) were interviewed during the months of January - March 2023.

Of the total 34 interviewees, 18 were Regional Center Directors and 16 were SAE Project Managers. Thus, the response rates were 86% for Regional Center Directors and 77% for SAE Project Managers. The interviews with Regional Centers Directors averaged at approximately 48 minutes, with a maximum of 1 hour and 45 minutes and a minimum of 20 minutes. The structured interviews with SAE Project Managers averaged at approximately 49 minutes, with a maximum of 1 hour and 12 minutes and a minimum of 29 minutes. The audio recordings were downloaded and transcribed with accuracy.

NVivo is a collaborative qualitative analysis software that researchers use to import, organize, explore, and connect their data. NVivo was used to complete the qualitative data analysis for the set of structured questions, some containing multiple related probes. Each response was analyzed for its manifest content. The codes for each question were geared at emphasizing, on a surface level, the content of participant responses to the interview questions without assigning latent themes based on the interpretation of NCCC team members. After this initial coding framework, codes were reviewed and the coding structure was refined and when applicable, codes were merged if there are significant similarities. Response frequencies were coded based on the number of occurrences of the coding structure, or how often it surfaced within and across participant responses. Therefore, certain frequencies will be higher than the overall sample size due to participants providing multiple answers. For example, if asked to share challenges of implementing the SAE Grant, participants may have mentioned three challenges for that single question, which would be coded in three separate themes/coding structures in NVivo. The coding structure with frequencies for each of the questions, presented during the interviews are located in Appendices A and B. Due to the limited sample size, a few questions will have lower frequencies responses i.e., frequencies of 1 or 2. However, those responses were kept because they were identified as salient themes.

Findings: Sub-objective 3.1.

The findings from interviews with Regional Center Directors and SAE Project Managers are grounded in several key thematic areas: 1. Racial, ethnic and linguistic disparities within Regional Center geographic areas and their underlying causes, 2. Root causes or factors that contribute to disparities, 3. The varied areas of focus of the service access and equity projects, 4. Measurement of disparity and equity outcomes, 5. Challenges in implementing SAE Grant projects within Regional Centers, 6. Successes experienced as a result implementing of SAE Grant projects, and 7. Concluding comments and recommendations to address racial, ethnic, and linguistic disparities at the regional level.

1. Racial ethnic and linguistic disparities experienced and their underlying roots/ causes

There were numerous reasons cited by respondents as to why their Regional Centers decided to submit a proposal(s) to DDS for its SAE Grant Program. Respondents for many of the Regional Centers indicated they submitted proposals to support and grow current equity outreach and projects that they had started and wanted to expand or continue. Others indicated that the SAE Grant Program offered them an opportunity to expand their outreach efforts and to find new ways to incorporate additional underserved populations that perhaps had not yet been a focused population

2. Root causes or factors that contribute to disparities in California's system

The Regional Center Directors and SAE Project Managers who were interviewed, identified several reasons that they thought disparities existed in their regional areas. One of the most foundational reasons identified was the Lanterman Act which was created in the 1960's primarily due to the successful advocacy of White (non-Hispanic) families. Respondents reported that the original system of services and supports was set up to serve that population. Now, the system is struggling to adapt to the changing demographics, interests, and needs of California's diverse population. Respondents indicated that communities may not find that the service menu offers supports that they want (are acceptable)

"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."

in terms of meeting the needs of their family and cultures.

Respondents stated that families that have members with IDD in many of the communities that experience disparities have to juggle multiple competing demands and circumstance that require prioritizing and problem solving. Several respondents indicated that so many of the families with whom they had contact were trying to find a place to live and ensure there was enough food to feed their families. Additionally, other basic services mentioned, such as transportation may not be sufficient or available to the families to get where they need to go to be determined eligible or to receive certain services. Lastly, respondents stated that services provided are often not made available to families by providers and staff who are from or are knowledgeable of the diverse racial, ethnic, and linguistic communities in their geographic locale which causes communication challenges and can lead to cultural barriers.

3. Varied areas of focus of service access and equity projects

"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."

Responses indicated that many SAE Grant projects were focused on community outreach and/ or connector programs to build capacity and

relationships in the diverse communities within the geographic area served by the Regional Centers. Some Regional Centers reported that they were able to allocate more time to support their SAE Grant activities through an enhanced case management program which temporarily decreased the caseload size for several of their staff. This allowed the case managers to support individuals and families with generic services and supports which helped the entire family while also focusing on the individual with a developmental disability. Regional Center Directors and SAE Project Managers reported that “targeted communities” found the extended outreach very effective throughout the duration of the grant and wanted outreach to continue after the grant funding ended. While not all could continue this more in-depth outreach and support, many Regional Centers were able to find ways to continue funding their SAE outreach programs with vendors and communities.

Note: Many communities resent and reject being targeted. Throughout this report the NCCC-MA Team will use the term communities of focus or identified community or population unless it is a verbatim quote.

Respondents reported that SAE projects used many linguistically and/or culturally competent approaches when implementing their grant(s) specifically in areas of supports, services, and project activities. Nearly all Regional Centers reported that they tried to incorporate elements of both culturally and linguistically competent approaches in their grant projects. Examples of the approaches used included ensuring that written materials were in the language reflecting the community of focus — using translators and cultural brokers, co-creating activities with the community, and others. Respondents for many Regional Centers mentioned that they found it challenging to gain the trust of the populations of focus due to historical racism and cultural preferences related to engaging with services outside of the family units and communities in which they live. Additionally, most of the Regional Center respondents indicated that they did or attempted to work directly with persons with IDD and their family members from racially, ethnically,

culturally, and linguistically diverse backgrounds when developing their grant projects.

Respondents stated that some of the SAE Grant activities and strategies were used to reach people with IDD and their families that were unknown or not receiving services through the Regional Center system. Many strategies were used to identify new people from diverse racial, ethnic, cultural, and linguistic backgrounds in efforts to increase access to services. Respondents voiced that through the SAE Grants, most Regional Centers provided some type of training and/or outreach (including through social media) to persons supported, families, advocacy and support groups, and vendor and provider groups. These activities were designed to reach families in various communities that were unknown to the Regional Center staff and programs. Many Regional Centers worked with their State Developmental Disabilities Council, County, and City staff, as well as local legislators, to find ways to reach these diverse populations. Respondents believed the outreach efforts served to build trust and enhanced existing relationships within the populations of focus.

4. Measurement of equity/disparity outcomes

Most respondents indicated that their Regional Centers did not have adequate data systems and tools, or staff with the expertise or time needed to analyze the results of their SAE Grants. Regional Centers basically relied on the reporting formats that were sent to them from DDS. Additionally, most respondents reported this data to be basic and focused on purchase of service (POS) with many important variables unreported (e.g., age, socio-economic status, and other cultural factors). Regional Center respondents expressed interest in improving their skills in data systems, collection, analysis, and use. While evaluation was not built into their grants, Regional Centers would have liked to find better ways to identify outcome data to understand how the state funds provided for the SAE Grant Program impacted their population, and to learn the overall effects of their grant project. Depending on the type of SAE project, Regional Center respondents stated that they generally had a low to moderate capacity, and one Regional Center attributed this in part to working through the San Diego Information

System (SANDIS) for collecting and analyzing data generated from their project.

Responses from Regional Centers indicated that solely tracking increases in POS to measure disparities is not an effective method because it does not inherently include cultural considerations and socio-cultural contexts. Other measures are needed to demonstrate increases in service availability, acceptability, accessibility, quality, and utilization among people with IDD and their families disproportionately impacted by racial, ethnic, and linguistic disparities. Note: The interview included questions framed from the Goode Disability Disparities Framework that probed the extent to which the SAE Grant projects differentiated disparities reduction using the five previously stated categories □ availability, acceptability, accessibility, quality, and utilization.

Respondents were asked if they used theory of change and logic models in their grant SAE projects. A theory of change is a comprehensive description and illustration of how and why desired change is expected to happen in a particular context. A logic model is a visual way to illustrate the resources or inputs required to implement a program, the activities and outputs of a program, and the desired program outcomes (short-term, intermediate, and long-term). Both are commonly used in grant development and evaluation. Nearly all Regional Center respondents indicated that either did not know about or did not specifically use a theory of change or a logic model to inform their grant projects. Across Regional Centers, no standard definition of disparity or equity existed, and neither was required in the

guidance for the SAE Grant proposals.

5. Challenges experienced with implementation and outcomes of projects

Regional Centers agreed that the SAE Grants should have a longer time frame. Most projects lasted about one year which was simply not enough time to determine if the activities of their SAE Grants would either begin or continue to benefit populations and communities of focus. As mentioned previously, Regional Centers respondents expressed that outcomes should not be solely defined in terms of POS dollars.

Regional Center respondents stated that their projects and outreach activities were limited in implementation because project activities were often added to the workload of existing staff who typically work a 9:00 a.m. to 5:00 p.m. business day. Respondents reflected that since many within the populations of focus work during the day, having staff working in the evenings and weekends would likely have been more effective, particularly for family engagement and education.

Other challenges reported by Regional Centers were focused on the ramifications of COVID-19 and the need to completely change from in-person activities to virtual. The COVID-19 pandemic significantly hampered outreach to people with IDD and/or their family members often due to lack of: 1) access to computers and/or understanding of how to access virtual platforms; and 2) trust by people with IDD and/or their family members was also mentioned as a barrier to participation.

“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.”

“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.”

Smaller Regional Centers operating within rural geographic areas reported that they have fewer staff and that it is difficult to assign staff who understand the complex circumstances related to the diversity, equity, and inclusion interests and needs specific to racial, ethnic, cultural, and linguistic backgrounds of the communities they serve.

“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.”

6. Successes and significant outcomes

“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.”

Respondents were asked to share some of their most significant outcomes in disparities reduction from their Regional Centers’ SAE project(s). Most Regional Centers indicated that disparity, as defined as POS dollars increases, were not quantifiable through their SAE Grants based on data they could generate. However, several reported some changes specific to identified populations in one or two service types.

“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.”

Nearly all respondents reported improved community outreach, more culturally competent practices used within their Regional Centers, and improved and new relationships with various communities. Additionally, nearly all reported a growth in their own and their employees’ understanding of disparities, their root causes, and culturally competent practices.

When asked, most Regional Center respondents view the SAE Grant Program as critical to advancing their work with diverse populations to decrease disparities among persons with IDD across racial, ethnic, cultural, and linguistic groups. Many Regional Centers welcome the oversight provided by DDS regarding grant accountability and outcomes. That said, respondents for Regional Centers would like to see: (1) changes made to the SAE Grant Program to include longer term grants and measurable results; and (2) more program consistency across all Regional Centers for SAE Grants that are basically the same (e.g., outreach, connector programs, and training). Respondents indicated that the SAE Grant Program allows Regional Centers to implement pilot projects. Once identified as successful, Regional Centers want DDS to provide ongoing funding for long-term investments to promote the systemic change that will improve the lives of underresourced and underserved communities.

Summary statement for sub-objective 3.1.

Respondents stated that their Regional Centers were appreciative of the opportunity to have these grants and found the work and outcomes to be helpful. Those interviewed were very clear that they have work to do in order to make POS expenditures

equitable across the different populations they serve but feel strongly POS should not be the only consideration. Many Regional Center Directors and SAE Project Managers reported that their older White (non-Hispanic) population was the highest users when measured by POS, and attributed this to the costs associated with out-of-home residential care. Respondents stated that residential care is not necessarily the type of supports and services that some families from specific racial, ethnic, and cultural groups prefer and want. Respondents were also clear that additional methods that appropriately respond to and measure disparities that go beyond POS are needed. Many reported that they did not intentionally focus their projects on other important aspects of disparities. All Regional Centers agreed that other measures are needed to demonstrate increases in service availability, acceptability, accessibility, quality, and utilization among people who experience racial, ethnic, and linguistic disparities.

- **Sub-objectives 3.2.** Conduct small group virtual listening sessions for families to elicit their experiences and insights on disparities and equity within the California IDD system of services and supports.*

Methods

To fulfill this sub-objective, the NCCC-MA team planned virtual listening sessions that were conducted statewide. The virtual listening sessions were specifically designed for families of persons who experience IDD across the lifespan to elicit experiences and insights on disparities and equity within the California IDDD system of supports and services. All listening sessions were structured to maximize accessibility, meet ADA compliance standards, and use plain language; and were offered in English and languages of preference of the participating families including ASL. In compliance with the terms of the DDS contract, the NCCC-MA Team subcontracted with California interpretation and translation vendors for this service. Consistent with principles and practices of cultural and linguistic competence *and* equity, incentives were offered to listening session participants. Families are often the only uncompensated and unpaid people at the policymaking table, even though they bring valuable knowledge and insights based

on their lived experiences. Each family member was offered a \$25.00 retail gift card of their choice after participating in the virtual listening session. This practice adheres to the following values and principles that advance equity.

NCCC Guiding Values and Principles

Community Engagement

Communities should economically benefit from collaboration.

Community engagement should result in the reciprocal transfer of knowledge and skills among all collaborators and partners.

Persons with IDD and Families

Families and persons with lived experience of IDD are the ultimate decision makers for supports, and services for their children and/or themselves and how they choose to live their lives.

The NCCC-MA Team planned and allocated resources to conduct a total of 21 virtual listening sessions for up to 420 families across geographic areas covered by Regional Centers. Participants were recruited through nomination by Regional Centers and CBOs, as well as self-registration using a web-based software. Regional Centers and CBOs identified **70** families to participate. Once information about the listening sessions was disseminated via the Internet, an additional **557** self-registrants were received. The NCCC-MA Team was initially excited to see the increase in registrants. However, after further examination of the data, it became evident that a significant number of these registrations was from out of the country and spam. The proliferation was most likely due to public listing that a monetary incentive would be offered to participants. The NCCC-MA Team conducted a careful review of registration data, confirmed eligible self-registrants, and contacted them to participate in the virtual listening sessions. It is important to note that there was attrition during the process to confirm and schedule the listening sessions. Some self-registrants and nominated participants did not respond to email invitations. In consultation with DDS, the NCCC-MA Team decided to include the self-registrants in the virtual listening sessions and to code their responses

separately from those families that were nominated by Regional Centers and SAE grantees.

The virtual listening sessions were scheduled to last approximately 90 minutes. In preparation for the sessions, registrants were provided an informed consent form and instructed to review and provide their electronic consent. Once the consent forms were received, web conferencing details were sent to registrants via email.

The virtual listening sessions were conducted using Zoom™ and ThoughtExchange™ web-based technologies. The sessions were conducted by NCCC-MA Team and a bilingual consultant who facilitated sessions in Spanish in response to family requests. The interviewer: (1) provided a brief overview of the purpose of the SAE Grant Program evaluation; (2) reminded participants the session would be audio- and video-recorded, as stated in the informed consent; (3) introduced the ThoughtExchange™ platform and played a four-minute instruction video on how the platform would be used. Once participants indicated they understood how the platform worked, the first question was launched on ThoughtExchange™. Participants were given 8-10 minutes to answer independently. After each question, participants were invited to discuss the question as a large-group on Zoom™. Each family received a \$25.00 electronic gift card for a retail establishment of their choice after participating in the virtual listening session.

Data collection and analysis

A total of 14 virtual listening sessions were conducted with family members in the May 2023 with a total of 70 participants. The number of participants per session varied. As previously described, the virtual listening sessions were conducted using web-based platforms — ThoughtExchange™ and Zoom™. The ThoughtExchange™ session allowed participants to respond to questions anonymously and then rate the “thoughts” that others in the group put forward.

Listening Session Format	Number of Sessions	Number of Participants
English language session facilitated via Zoom™	11	38
Spanish language session facilitated via Zoom™	3	7
English language session facilitated via ThoughtExchange™	1	25

NVivo was used to complete the qualitative data analysis for the set of structured questions, some containing multiple related probes. ThoughtExchange™ was used to generate reports from responses collected during the virtual listening sessions. Transcripts were carefully reviewed and coded by the NCCC-MA Team. Each response was analyzed for its manifest content. Participants’ responses to the interview questions were analyzed using a three-step process. The first step involved coding focused on the content of the participants’ responses to each of the questions without designating underlying themes based on interpretation of NCCC team members. Secondly, after this initial coding was completed, codes were reviewed and the coding structure was refined as needed. Lastly, when appropriate, codes were merged if there were significant similarities. This three-step coding process contributed to the robust organization and synthesis of information and the comprehensive presentation of participants’ perspectives.

Findings: Sub-objective 3.2.

The findings from virtual listening sessions with families included analysis of data from 70 participants — SAE Grant family participants (n=32) and family recipients of Regional Center services (n=38). Overarching themes were found between the two groups and were categorized as follow: 1. Availability and timeliness of supports and services, 2. Accessibility of supports and services, 3. Cultural and linguistic considerations, 4. Usefulness and impact of supports and services, 5. Quality of supports and services, 6. Acceptability of supports and services, and 7. Recommendations for improvements. The experiences and insights

gathered from families document the multifaceted challenges and opportunities within the California system of supports and services for persons who experience IDD across the lifespan and their families. It is uncertain if some of those designated as family recipients of Regional Centers services were also participants in the Regional Center's SAE Grant Program. These participants were not presented with an opportunity to indicate that affiliation in initial recruitment efforts. The coding structure with frequencies for each of the questions, presented during the listening sessions are located in Appendix C.

1. Availability and timeliness of supports and services

"Delaying is denying and misinformation for immigrant communities about resources available can create an insurmountable barrier for access."

The majority of participants highlighted challenges related to the availability of supports and services, often due to waitlists, vendor availability, and processing times. The term "denial by delay" emerged as a recurring experience described by expressing their frustration with the delays and time lag between identifying needs and receiving supports and services, sometimes spanning months or longer. Participants indicated lack of information and communication about available supports and services as a barrier, most notably from service coordinators. Some participants felt they did not qualify for services due to lack of information, thus deterring them from pursuing the services they needed.

2. Accessibility of supports and services

"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."

A number of participants highlighted the pivotal role that service coordinators play in their ability to access services. Service coordinators were often described and seen as gatekeepers. Participants noted that a knowledgeable and supportive service coordinator could facilitate access to supports and services, while conversely, difficulties in communication with service coordinators hindered timely access. Some participants reported that they assumed significant responsibility themselves to advocate for the interests and needs of their family member(s) with IDD to access supports and services. Thus, navigating complex systems, especially for families lacking the resources and/or self-advocacy skills, posed an additional barrier. Lastly, a recurring concern reported by participants was the scarcity of available service providers or vendors. Participants indicated that even when services were approved, the lack of providers or vendors posed significant challenges leading to delays and gaps in accessing essential supports and services.

3. Cultural and linguistic considerations

"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?"

The majority of participants expressed the need for greater cultural considerations in the provision of services and supports. Participant stressed the need for more culturally sensitive and inclusive services that respect their values and traditions. Some participants felt that assumptions were made about their service preferences without explicit inquiry and due consideration for their family's cultural background.

A number of issues regarding language access were raised by participants including: 1) limited availability of resources in languages other than English; 2) disparities in access to services for non-English speakers; 3) inaccurate translation and interpretation services that

did not consistently capture the cultural and linguistic nuances in written documents and oral communication.

4. Usefulness and impact of supports and services

“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.”

The majority of participants generally rated the supports and services they received as “useful” to “very useful.” These participating families cited personal experiences that indicated the positive impact on persons with IDD who are receiving services such as improved social interactions, providing relief (respite care), and enhanced quality of life. The majority of participants acknowledged the crucial role of Regional Centers in the provision of essential supports and services. However, the process of obtaining these supports and services was cited as an area of improvement.

It is important to note that the Self-Determination Program was frequently highlighted as a positive aspect of services that provided greater flexibility and autonomy, and enabling families and persons who experience IDD to make decisions and shape their own supports. The majority of participants indicated that they would recommend Regional Center services to other families. While this reinforces the essential role that Regional Centers play, they are the only or primary source for such IDD supports and services in the California. Most participant recommendations came with the caveat that families must be proactive to understand Regional Centers’ policies, trends, and timelines in order to effectively navigate the system. Participants stressed the importance of self-advocacy in successfully accessing and benefiting from Regional Center services.

5. Quality of supports and services

“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.”

Participant responses indicated that the quality of supports and services varied greatly. The majority of participants indicated that their experiences in California’s IDD service system ranged from “fair” to “varying.” They reported that service quality depended a number of factors on several factors — inconsistencies in the quality of services of providers and/or vendors and how well staff were trained. Some participants noted a lack of choice in service providers, particularly for specialized services. Overall, families wanted more consistent high-quality supports and services.

6. Acceptability of supports and services

“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.”

Participants indicated that the acceptability of supports and services varied greatly, with responses ranging from “somewhat acceptable” to “acceptable.” Several factors influenced participants’ view of accessibility including the extent to which services align with individual interests and needs, personal effort invested, and ease of access. It is important to note that families expressed a high rating of acceptability for the Self-Determination Program attributed to increased autonomy, choice, and active involvement in decision-making. Lower acceptability ratings were often associated with lack of staff training, poor communication, and delays in responses need-based requests.

7. Recommendations for improvement

“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 accidentally hearing something from someone else. Like, ‘Wait a minute. That’s offered? That’s an option?’”

Participants provided a comprehensive set of recommendations to create a more inclusive, responsive, effective, and culturally and linguistically competent IDD system. Participating families underscored the importance of transparency in the supports and services offered, pointing out the need for clear communication about available options. They emphasized the need for **increased staff training**, particularly for service coordinators who play a crucial role in the access to services. Participants strongly emphasized the critical **need to equip staff with the knowledge and skills to engage families effectively** in ways that are responsive to diverse cultures and languages. Educational outreach was also a recurring recommendation that emphasized the need for **increased efforts to educate families** about the available supports and services, and **providing resources for families to help navigate the complex systems**. Participants called for more **family-centered approaches** that focused on the interests, needs, and perspectives of families and persons who experience IDD. They emphasized: 1) the importance of partnering and **involving families in decision-making processes**; and 2) listening to their **interests and needs when planning, designing and providing supports and services**. Other recommendations included reduced caseloads, improved cultural and linguistic competence, implementation of flexible service models like the Self-Determination

Program, and standardized supports and services across all Regional Centers.

Summary statement for sub-objective 3.2.

The listening sessions with families of persons with IDD across the lifespan provide a candid assessment of their experiences in California’s complex IDD system, and recommendations for improving supports and services that they need and prefer for themselves and for their family member(s) with IDD. Participants described both strengths and challenges within the current system. Ultimately, these findings illuminate a shared journey that unites families, persons who experience IDD, service coordinators, providers, vendors, policy makers, and other constituents in the endeavor to build a system of supports and services that is accessible, responsive, culturally and linguistically competent, of high quality — importantly more equitable.

- **Sub-objective 3.3.** Conduct structured interviews with staff of the Department of Developmental Services to: 1) review the Department’s vision for equity and disparity reduction; 2) elicit their views on the contributing factors to disparities including root causes; 3) ascertain view and evidence of the overall impact of the SAE Grant Program; 4) gauge the Department’s willingness and authority to rethink how the SAE Grant Program is structured, administered, and evaluated; and 5) explore the feasibility of changing approaches and components of the SAE Grant Program based on evaluation results and recommendations.*

Methods

The NCCC conducted structured interviews with DDS staff to elicit data on 1-4 above and other salient data based on the Goode Disabilities Disparities Framework. Interview questions are in Attachment B. A total of eight DDS staff were initially identified to participate in the structured interview process with the NCCC-MA Team. A total of six interviews were completed from November 4, 2022 -January 19, 2023 (one staff member was exempted from the interview process). The structured interviews were approximately 51 minutes, with a maximum of 1 hour and 23 minutes and a minimum of 41 minutes.

DDS SAE Team	DDS Staff in Other Divisions
Leinani Walter, Chief Equity Officer	Jessica Love, PhD, Research Data Supervisor II
Linda Gutierrez, Cultural Specialist	Caroline Castaneda, Assistant to the Director
Mayra Ochoa, SAE Grants Manager	Rapone Anderson, Manager CEA, Office of Community Operations (retired)

Findings: Sub-objective 3.3.

This sub-objective presents the analysis of the DDS interviews that were conducted and a comparative trend analysis across all qualitative data sources in the evaluation. The coding structure with frequencies for each of the questions, presented during the interviews are located in Appendix D.

Analysis of findings from DDS staff interviews

- **Definition of equity**

Within the Department, there is neither an explicit definition of equity nor consensus on what equity means within the IDD context.

- **Shared vision for achieving equity**

Within the Department, there are similar elements for a vision to achieve equity in California's IDD system. However, consensus has not been reached on exactly what is the vision for equity, and how best to engage populations and communities that are most impacted by inequities in a meaningful visioning process statewide.

- **The role of disparities reduction in achieving equity**

Disparities reduction, and corresponding initiatives to address them within the Department, are not limited to the SAE Grant Program — nor should they be (refer to Appendix E). One dedicated grant program, even one that is funded at \$11 million dollars annually, simply is not capable of addressing the entrenched and complex array of disparities that disproportionately affect persons who experience IDD and their families from specific racial, ethnic, and linguistic groups in California. While disparities reduction and equity are related, they are not the same. The Department does not currently have a logic

model that correlates disparities reduction and its relationship to achieving equity, nor does it employ or require change theories in the design, implementation, and evaluation of the SAE Grant Program.

- **The extent to which the design of the SAE Grant Program was informed by the evidence base on disparities reduction and cultural and linguistic competence**

From the interviews, it does not appear that the extant evidence on cultural and linguistic competence and disparities reduction was taken into consideration in the design of the SAE Grant Program. As previously delineated, not only does the IDD space lag far behind other fields in the development, implementation, and evaluation of evidence-based practices that specifically focus of racial, ethnic, and linguistic groups that disproportionately experience disparities, it also has not defined equity in any meaningful and measurable way. Current evidence in other fields clearly indicate that the IDD space should respond to disparities reduction, like cultural competence, as developmental processes that occur over time *not in 1-2 year increments* as the SAE Grant Program was designed. Moreover, the SAE Grant Program encouraged Regional Centers and CBOs to apply for different grant categories which mitigated a focus on longer-term focused implementation and data gathering to ascertain effectiveness.

- **Root causes and contributing factors to disparities experienced by persons with IDD from specific racial, ethnic, linguistic groups in the California IDD system**

As stated in the interviews, the root causes of disparities experienced by persons with IDD and their families are myriad and include but are not limited to (a) poverty; (b) racism, ableism and other "isms"; (c) complexity of the IDD system in

California; (d) insufficient number of culturally and linguistically competent staff; (e) geographic locale within the state; (f) power dynamics and structure of the Regional Center system of service delivery; (g) the structure of the Lanterman Act and its amendments; and (h) cultural beliefs and practices of families about disability and the types of supports and services they want, need, and prefer.

Consistent with NCCC-MA Team assertions, it must be recognized and accepted that some of the contributing or causal factors for disparities in developmental disabilities supports and services are neither under the auspices nor control of DDS. It is essential to ask and answer the question: *Disparities in what?* Are the disparities rooted in five areas of availability, accessibility, acceptability, quality, or utilization? What is the nexus of these five areas and their impact on racially, ethnically, and linguistically diverse persons with IDD and their families? Most importantly, which disparities are actually under the auspices of DDS to effect change, which will require close coordination with other health, mental, education, and human services systems in California, and how can existing resources be effectively allocated?

- ***Feasibility for DDS to restructure approaches and components of the SAE Grant Program***

DDS staff who were interviewed stated that making substantive changes to the SAE Grant Program ranged from “very feasible” to “feasible.” While these staff expressed commitment to a path forward, making such changes are not limited to DDS alone. Making changes in the SAE Grant Program will require: (1) the political will and endorsement of the state legislature, persons with IDD and their families, and other key constituencies; (2) significant infrastructure changes including increased staffing capacity with the SAE Division and others DDS divisions and offices responsible for contracting, data collection and monitoring, provision of technical assistance, and community engagement; and (3) redistribution of dedicated resources in an equitable manner in initiatives, supports, and services that actually decrease disparities *and* increase equity over time.

- ***Overall impact of the SAE Grant Program in reducing disparities***

As gleaned from the interviews, the evidence that the SAE Grant Program reduced disparities varied significantly. Examples ranged from “minimal impact” to specific examples of community engagement such as “building trust within marginalized communities” that did not previously exist and “increasing knowledge” of services offered by Regional Centers. While these are important outcomes, they do not raise to the level of disparities reduction consistent with the intent of the AB legislation X21 including increases in POS.

- ***Extent to which purchase of service (POS) expenditures accurately identify disparities between racially, ethnically, and linguistically diverse populations served by DDS***

Interview responses all indicated that POS identified disparities to some extent but should not be relied upon as an accurate standalone measure. Reasons stated included but were not limited to:

(1) limited data collection and analysis capacity within DDS and Regional Centers; (2) only measures what Regional Centers are purchasing; (3) many factors affect disparities such as geographic, cultural, Regional Center policies, and local politics; (4) the vision for disparities reduction has to expand beyond POS; and (5) POS highlights that DDS has not met peoples’ needs – why are there so many people of color without POS? These responses align with those collected from interviews with Regional Center Directors and SAE Grant Managers. Moreover, staff responses give credence to fact that disparities need to be analyzed beyond race, ethnicity, and languages spoken because their causes are long-standing and multifaceted.

- ***The extent to which the SAE Grant Program was designed to reduce disparities at the following levels.***

» ***Individual.*** Interview responses ranged from “to a great extent,” “somewhat,” to “little to none.” DDS staff indicated that some aspects of the SAE Grant Program are designed to address disparities at the individual level such as the Connector projects that work one-on-one with

people. Others stated that they were not sure, and that impacting individuals is a growth area.

- » **Family.** Interview responses ranged from “to a great extent” to “little to none.” Examples included parent and family support groups and networking with other families.
- » **Community.** Interview responses ranged from “somewhat” to “not sure.” DDS staff were unsure if the program was designed to reduce disparities at this level or it is a by-product of building relationships; and cited examples of educational awareness and video initiatives.
- » **Organizational.** Interview responses ranged from “to a great extent,” “somewhat,” to “little to none.” The most affirmative statement linked the SAE Grant Program to the addition of CBOs that significantly improved knowledge and relationships with Regional Centers. On the other end of the spectrum the SAE Grant Program was viewed to reduce disparities for individuals and families.”
- » **Systems.** Interview responses ranged from “somewhat” to “little to none.” DDS stated that they: were unsure if the SAE Grant Program was designed to impact systems but had effects to some extent on organizational and systems change; and the grant program has not made shift at the systems level.

The overall responses by DDS staff indicate that the SAE Grant Program, from its inception through implementation in FY 2019-2020, was not designed to effect disparities reduction at the multiple levels within the California system of services and supports.

- ***What logic model was used by DDS for disparities reduction at the individual, family, community, organizational, and systems levels***

DDS reported that it neither uses a logic model nor requires grantees to use a logic model to advance equity and reduce disparities at any of the above levels in the implementation of the SAE Grant Program.

- ***The extent to which differentiates disparities reduction using categorical designations of availability, accessibility, acceptability, quality, and utilization***

- » **Availability.** Interview responses fell solidly in two groups “to a great extent” and “somewhat.” Responses included: (1) Regional Centers were viewed as focusing heavily on availability of services; and (2) emerging recognition that availability is closely linked to choice, self-determination, culture, and life experiences.
- » **Accessibility.** Interview responses ranged from “to a great extent,” “somewhat,” to “no/not sure.” Examples provided ranged from the importance of plain language communication, disability accessible, and interpreters for languages other than English and sign language. Other statements indicated: (1) The Department ensures language interpretation but physical accessibility may not be taken into consideration; and (2) Regional Centers work differently and this is a source of trouble for the system.
- » **Acceptability.** Interview responses ranged from “to a great extent,” “somewhat,” “little to none,” and “not sure.” Staff acknowledged that the COVID-19 pandemic impacted service delivery in significant ways. Others indicated: (1) the recognition for the need for different service types; (2) Regional Centers are making efforts to provide services in culturally and linguistically competent; and (3) an emphasis on acceptability is not really part of the Department’s narrative.
- » **Quality.** Interview responses ranged from “to a great extent,” “somewhat” to “little to none.” Staff responses varied from the role of the Department’s Quality Assurance Unit, incentives for Regional Centers, and not enough attention to quality from the lens of the populations of focus of the SAE Grant Program.
- » **Utilization.** Interview responses were grouped in two categories “to a great extent” and “somewhat.” Staff stated that a lot of analyses is performed on utilization emphasizing race and language; it is an area of strength because utilization is easy to measure; some groups and centers are using it more than others and “what doe DDS do for groups who do not utilize” supports and services.

The overall responses indicate that the SAE Grant Program does not employ a framework that critically examines the scope, depth, and complexity of disparities beyond race, ethnicity, and language of persons with IDD across the life course and their families.

- ***What measures are used by DDS to document SAE grantees' use of culturally competent approaches in the following grant types***

- » ***Translation.*** All DDS staff indicated that they were not sure that culturally competent approaches were documented by SAE grantees – both Regional Centers and CBOs.
- » ***Outreach.*** Staff responses highlighted pre- and post-survey for specific activities such as training; and the Department does not know unless it is in reports submitted by Regional Centers and CBOs.
- » ***Workforce capacity.*** Staff responses cited measures for bilingual staff hired and no explicit measures are in place.
- » ***Parent education.*** Staff responses indicated no explicit measures.
- » ***Promotora.*** Staff responses indicated measures of cultural competence relied on project experts and an assumption that are experience with the population of focus; and exactly how Promotoras are helping, measures, are not captured, and there are no explicit measures.
- » ***Family/consumer support services.*** Staff responses indicated no explicit measures.

The overall responses indicate that DDS did not employ any consistent measures to ensure that the SAE grantees use culturally competent approaches to implement projects. Given the population of focus of the grant program culturally competent approaches are necessary.

- ***What measures are used by DDS to document SAE grantees' use of linguistically competent approaches in the following grant types***

- » ***Translation.*** Staff responses indicate no explicit measures.
- » ***Outreach.*** Staff responses indicate no explicit measures.

- » ***Workforce capacity.*** Staff responses indicate no explicit measures.
- » ***Parent education.*** Staff responses indicate no explicit measures.
- » ***Promotora.***
- » ***Family/consumer support services.***

The overall responses indicate that DDS does not have measures to ensure that the SAE grantees use linguistically competent approaches to implement projects. Given the population of focus of the grant, and the number of languages spoken in California, linguistically competent approaches are necessary.

- ***To what extent did the design of the SAE Grant Program consider disparities reduction as a developmental process that occurs over time.***

Interview responses ranged from “to some extent,” “little to no extent,” and “not sure.” Examples include: (1) The SAE Grant Program is legislatively mandate and has permanent funding source, which denotes time was a consideration; (2) One-two year duration of grant projects is an administrative limitation; (3) Clearly not enough time for project implementation as it takes six months for startup; (4) The developmental nature of disparities reduction was not taken into consideration in the design of the program.

The overall responses suggest that DDS may not have used evidence-based policy and practice to inform the design of the SAE Grant Program.

- ***How feasible is it for DDS to restructure approaches and components of the SAE Grant Program based on the independent evaluation?***

Responses by all DDS staff clearly stated that restructuring the SAE Grant Program was either “highly feasible” or feasible. Staff cited the commitment of leadership, program staff, and annual quality review and improvement. The only caveat was continued allocated funding and budget priorities above the Department level.

At the time this report was being finalized, DDS was considering which recommendations, based on the Interim report submitted by the NCCC-MA team on 4/5/23, could be included in the FY 2023-2024 SAE Grant RFP and guidance.

- **Describe the most significant challenges in implementing the SAE Grant Program**

The interviews revealed three primary challenges including: (1) Insufficient staff within DDS to perform all of the functions associated with a grant program. Prior to the launch of the SAE program, DDS had primarily issued contracts; (2) Lack of diversity and representation at the leadership level within Regional Centers; (3) Limited collaboration and partnerships between Regional Centers and CBOs; (4) Using POS as a primary metric to measure the impact of the program; and (5) Decisions on how to allocate the 11 million funding to Regional Centers and CBOs.

The identified challenges point to: the type of infrastructure necessary to administer, monitor, and evaluate a novel grant program; using an equity lens in the allocation of funding to what may be viewed as competing interest groups — Regional Centers vs. CBOs that represent the marginalized communities of focus of the grant program; and adhering to the legislation by using POS as a primary metric.

- **Describe the most significant challenges in evaluating the SAE Grant Program**

Consistent with the challenges stated in the implementation of the SAE Grant Program, DDS staff who were interviewed identified limited infrastructure capacity and sole emphasis on POS as major challenges. All staff singled out POS stating:

- » “It is challenging to work on a program that is heavily judged by POS.”
- » “The huge emphasis on POS as a metric. Many of these project types are almost impossible to show a direct connection to POS change.”
- » “When it comes to evaluation ... 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.”

Inadequate program staffing compromises the capacity to monitor quality, track outcomes, provide technical assistance, and evaluate the SAE Grant Program. POS continues to provide one metric when the scope and complexity of disparities require multiple measures to document effectiveness and outcomes.

- **Disparities outside the Department’s control that impact persons with IDD and their families from racially, ethnically, culturally, and linguistically diverse groups**

Staff responses identified financial challenges, unstable housing, healthcare needs, Regional Center autonomy, the impact of internal (within the Department) and external (Federal) regulations and laws, and personal and/or cultural preferences for supports and services.

As stated previously in the Assertions section of the report (pages 15–16), it must be recognized and accepted that some of the contributing or causal factors for disparities in developmental disabilities supports and services are neither under the auspices nor control of California DDS.

Findings: Sub-objective 3.3. analysis of findings from DDS staff interviews

The DDS structured interviews included the following question: **In addition to the SAE Grant Program, what other efforts is the Department undertaking (including organizations with which it is working) to: a) increase equity and b) decrease disparities?** The Department submitted a detailed a document that delineated the names of the services, programs, initiatives, a brief description, and the fiscal resources invested in such efforts. This response is included in Appendix E. It is provided separately because the information was not collected in the interview process.

- **Sub-objective 3.4.** Use Goode’s *Disability Disparities Framework* as a basis for questions to administer a survey for CBOs and conduct listening sessions with Regional Center Cultural Specialists and CBOs that include but are not limited to: 1) describe the role they play in disparity reductions within the California IDD system of supports and services; 2) define equity within the context of IDD supports and services; (3) describe the root causes of racial, ethnic, and linguistic disparities; and (4) describe the role and impact of the SAE Grant Program; and (5) offer recommendations to enhance the SAE Grant Program.*

Methods

Listening sessions

The NCCC-MA Team conducted virtual listening sessions for Regional Center Cultural Specialists and CBO staff responsible for their SAE Grant projects. DDS provided contact information for both groups. The NCCC-MA Team communicated via email and telephone to confirm that these individuals were still on staff and responsible for the grant during FY 2018-2019 and 2019-2020. Once confirmed, the potential participants were contacted via email to register for a listening session using a Google forms booking page. The NCCC-MA Team created two separate booking pages for Cultural Specialists and CBO staff members. Potential Cultural Specialist participants were instructed to select from the following dates: November 14, 2022 or December 13, 2022 and CBO staff were instructed to choose either December 8, 2022 or December 9, 2022. The registration email invitation was sent to 21 Regional Center Cultural Specialists and 40 CBO grantees.

The Google forms also included an informed consent section, and participants were instructed to review and provide their electronic consent during registration. If the Cultural Specialists and

CBO staff members did not respond, reminder emails were sent. After the completed registration form was received, web conferencing details were sent to participants.

The listening sessions were conducted virtually on Zoom™ with designated NCCC-MA Team members using ThoughtExchange™. ThoughtExchange™ is a hosted software platform that allows participants to engage with one another in structured online interactions. With this platform, participants can independently and anonymously share their responses to questions in what is referred to as an *Exchange*. Each *Exchange* was created by a member of the NCCC team, referred to as the *Exchange Leader*, using the IRB approved questions.

ThoughtExchange™ rooms are virtual environments allowing *Exchange Leaders* to launch Exchanges to engage participants in meaningful conversations about matters impacting them. Participants accessed and participated in the Cultural Specialist and CBO ThoughtExchange™ forums using three methods: (1) a ThoughtExchange™ link was pasted

in the Zoom™ chat for participants to access using their web browser, (2) participants could join the ThoughtExchange™ using their web browser by going to tejoin.com and entering a 9-digit code presented on screen, and (3) a QR code was also presented on screen for participants to scan and participate using their phones. Participants then answered the questions, which were anonymous to the other participants. These anonymous comments were shared and rated by other participants. This process allows for an immediate *quantitative lens on qualitative data*.

The listening sessions were scheduled to last approximately 90 minutes. At the start of the listening session, the interviewer provided a brief overview of the evaluation and reminded participants that the session would be audio and video-recorded, as stated in the informed consent process and form. The interviewer then briefly introduced ThoughtExchange™ and played a four-minute instruction video to explain how the platform would be used during the listening session. Once participants indicated that they understood how the platform worked, the first question was launched on ThoughtExchange™. Participants were given 10 minutes to answer independently in ThoughtExchange™. After each question, they were invited to discuss each question as a large group on Zoom™.

Two Cultural Specialist listening sessions were conducted on November 14, 2022, and December 13, 2022 with 9 and 7 participants, respectively. In total, there were 16 participants in the listening sessions for a response rate of 76%. The Cultural Specialist listening sessions averaged approximately 94 minutes, with the session lasting approximately 1 hour and 35 minutes on November 14, and 1 hour and 32 minutes on December 13.

Two CBO listening sessions were conducted on December 8, 2022, and December 9, 2022 with 13 and 14 participants, respectively. In total, there were 27 participants in the listening sessions for a response rate of 68%. The CBO listening sessions averaged approximately 110 minutes, with the session lasting approximately 1 hour and 44 minutes on December 8th, and 1 hour and 56 minutes on December 9th.

ThoughtExchange™ was used to generate reports which reveal the responses shared and the ratings that occurred during all of the listening sessions. These reports are included in Appendix F for Cultural Specialists and Appendix G for CBOs.

CBO Survey

The NCCC-MA Team administered an online survey to CBO staff responsible for the SAE grants. The survey was designed to gain information on the implementation and outcomes of projects funded in FY 2018-2019 and FY 2019-2020. Qualtrics was used to administer the survey online. The link was disseminated to 53 CBO staff members through contact information provided by DDS and confirmed by the NCCC-MA Team. A total of 34 surveys were completed by CBO staff, for a response rate of 65% and 30 CBOs were represented. The survey opened on September 13, 2022, and closed on December 22, 2022. Descriptive statistics were conducted for the demographic questions which were quantitative. NVivo was used to complete the qualitative data analysis with response coding and frequencies reported. A summary and Tables 1-40 of CBO survey findings are included in Appendix H.

Findings: Sub-Objective 3.4.

Analysis and summary of findings from cultural specialists listening sessions

The findings from the listening sessions with Cultural Specialists (n=16) are grounded in the following key thematic areas: 1. Definitions of equity, 2. Root causes or factors that contribute to disparities, 3. The role of Cultural Specialists in disparities reduction, 4. Involvement in the SAE Grant Program, and 5. Recommendations for improvements. The experiences and insights gathered from Cultural Specialists present a view of the opportunities and challenges that can lead to a more equitable system.

1. Definitions of equity

“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.”

Participants offered various definitions of equity which were primarily centered around personalized support, inclusion, autonomy, empowerment, and the removal of barriers. Participants emphasized that equity, especially in the context of IDD, involves providing individualized services that are responsive to the unique needs, preferences, and barriers of each person and family. They expressed the significance of empowerment and autonomy, which involves recognizing and supporting the power of persons who experience IDD and their families to make their own decisions about their lives, while providing them with the necessary tools and resources. The importance of eliminating barriers was highlighted as crucial for equitable services, pertaining to both day-to-day obstacles and disparities arising from systemic issues. Ultimately, participants provided an insight into how different Regional Centers and their staff conceptualize equity for persons with IDD and their families.

Note: Overall data analysis completed by the NCCC-MA Team points to the fact that there is neither a shared definition/framework for equity among Regional Centers and other providers of supports and services nor within DDS and the California IDD system overall.

2. Root causes or factors that contribute to disparities

“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.”

Participants expressed that disparities within California’s IDD system arise from a complex interplay of factors. Notably, lack of education and limited awareness about Regional Center services, multiple languages spoken other than English, and misinformation were highlighted as barriers that hinder service access, and thus contribute to disparities. Historical oppression, stigma, and marginalization were stressed as deeply rooted causal factors that have systematically excluded persons with IDD and their families from specific racial, ethnic, and cultural groups and perpetuated disparities. The historical focus on White (non-Hispanic) populations and its impact on the design of the current system of supports and services was identified as factor in excluding the needs and interests of other culturally and linguistically diverse communities. Participants also cited the complexity of navigating the existing system and the lack of culturally and linguistically competent supports and services further hinder accessibility, acceptability, and utilization of supports and services for persons with lived experience of IDD and their families. Cultural beliefs, socioeconomic status, geographical barriers, and mistrust of government were also mentioned as factors that affect how families perceive and engage with supports and services. Overall, participants revealed a multitude of root causes or factors that contribute to disparities within California’s system of supports and services for persons with IDD and their families.

Note. Overall, participants described numerous root causes or factors that contribute to disparities. These must be taken into consideration using the definition of root causes put forth by the NCCC-MA Team. Root causes

are systemic. The SAE Grant Program must be viewed as only one effort within California State Government to address the root causes of disparities that affect the system of IDD supports and services.

Root causes of inequities include intrapersonal, interpersonal, institutional, and systemic mechanisms that organize the distribution of power and resources differentially across lines of race, gender, class, sexual orientation, gender expression, disability, and other dimensions of individual and group identity.

3. Role of cultural specialists in disparities reduction

“To be the bridge between the community and the Regional Center. Support families and Regional Center staff when asking or SC [Service Coordinator] providing services. To be able to identify disparities among our families in the Regional Center.”

Participants expressed that the role of Cultural Specialists in reducing disparities within the California IDD system is multilayered and essential. Participants indicated that, as Cultural Specialists, they are expected to take a leadership role and seen as key figures in identifying and addressing systemic barriers that contribute to disparities. Participants stated that Cultural Specialists facilitate communication, foster collaboration among different groups, advocate for change, and validate the struggles of underserved communities. Participants noted that Cultural Specialists inform Regional Centers and DDS about community needs and provide recommendations for more equitable services. Overall, Cultural Specialist described the various aspects of their roles and responsibilities, emphasizing advocacy, collaboration, community engagement, identifying disparities, being a liaison, and facilitating change.

Note: The involvement of Cultural Specialist in the SAE Grant Program varies depending on the practices within Regional Centers. Given

the essential roles described by participants of the listening session, consideration should be given to requiring that Cultural Specialists have defined roles and devote a percentage of their time to SAE Grant Programs within Regional Centers.

4. Involvement in the SAE Grant Program

“As the CS [Cultural Specialist], 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.”

Participant described various levels of involvement within the SAE Grant Program. They reported playing key roles in project development, grant writing, budget management, and project oversight. Participants noted that they were responsible for ensuring successful implementation, project monitoring and progress, and reporting outcomes. These responsibilities varied from: a) recognizing community needs, b) collaborating with different partners, c) identifying gaps that need to be translated into grant proposals and project, d) close collaboration with CBOs, parents and families, and vendors, and e) serving as liaisons to ensure the smooth flow of information in their positions with Regional Centers and multiple constituency groups. Overall, participants provided insights into the ways in which they have been involved in the SAE Grant Program, with the most common roles and responsibilities being project development, grant writing, collaboration, community engagement, and strategic oversight.

5. Recommendations for improvement

“DDS to encourage Regional Centers to start vendoring that have worked for the CLD [culturally and linguistically diverse] population. In order for the CLD population to access services, whatever service that has been implemented and found successful should become an ongoing service”

Participants offered valuable recommendations to DDS on strategies to reduce disparities. They stressed the importance of understanding and addressing the unique needs of persons with IDD and their families across diverse racial, ethnic, cultural, and linguistic groups and the specific disparities present in each Regional Center. Participants recommended that DDS do more to ensure cultural and linguistic competence across the SAE Grant Program. Culturally and linguistically competent approaches are necessary to improve accessibility, provide information about materials in various languages, and strengthen community presence. The following recommendations were offered by participating Cultural Specialists. Note they are not listed in priority order.

Cultural Specialists Recommendations for SAE Grant Program Improvement
Increase collaboration between Regional Centers and CBOs
Successful SAE Grant projects should become vendor services accessible to culturally and linguistically diverse populations
Funding for direct services
Extending funding periods from 1-2 year intervals
Allowing Regional Centers to allocate funds locally
Improved communication between DDS and SAE grantees including clarity and frequency
Increased access to data and utilization of such data to inform grant applications across the state
Center “clients” (persons with lived experience of IDD and their families) and underserved communities in decision-making

Most notably, participants emphasized the importance of DDS prioritizing SAE Grant projects that are centered on and responsive to local disparities, rather than disparities statewide. This approach is seen as ultimately contributing to a more equitable system of supports and services for persons with IDD and their families.

In conclusion, the listening sessions with Cultural Specialists paint a portrait of 1) how equity is perceived and defined across Regional Centers, 2) the root causes of disparities, 3) the pivotal role of Cultural Specialists in disparities reduction, 4) their involvement with the SAE Grant Program, and 5) recommendations for improving the California's system of supports and services for persons with IDD, across the life course, and their families from diverse racial, ethnic, cultural, and linguistic communities. Participants' recommendations reflect a strong call to action for disparities reduction projects and statewide initiatives that are culturally and linguistically competent.

Analysis and summary of findings from CBO listening sessions

The findings from the CBO listening sessions (n=27) are grounded in the following thematic areas: 1. Root causes or factors that contribute to disparities, 2. Successes of the SAE Grant projects, 3. Barriers encountered in the SAE Grant projects, 4. Effectiveness of the SAE Grant projects in increasing equity, 5. Effectiveness of the SAE Grant projects in decreasing disparities, and 6. Recommendations for improvements. The experiences and insights gathered from CBOs offer a description of the dynamics between CBOs with Regional Centers, families, DDS, and other community partners, and provide strategies to strengthen the SAE Grant Program.

1. Root causes or factors that contribute to disparities

"Difficulty navigating the system. Confusing information. Lack of central system. People don't understand what is available or how to access services."

Participants stated that disparities that affect persons with IDD and their families are rooted within complex and interrelated factors. The primary challenges identified across CBOs participating in the listening sessions are: a) the lack of cultural and linguistic competence, b) systemic racism, c) implicit bias, d) complexity of the systems that support persons with IDD and their families, e) lack of accessibility, f) income disparities, and g) lack of trust of Regional Centers, providers, and governmental entities such as DDS. Participants consistently underscored that the IDD system of supports and services are complex, difficult to navigate, and create access barriers — particularly for families that reside in underresourced communities and made vulnerable due to poverty. System complexity contributes to unmet needs because families do not know what to ask for or services for which they are eligible. Participants stated that lack of trust in governmental organizations, combined with the historical and systemic issues associated with minoritized communities, further widens barriers.

Note. Overall, participants described numerous root causes or factors that contribute to disparities. These must be taken into consideration using the definition of root causes put forth by the NCCC-MA Team. Root causes are systemic. The SAE Grant Program must be viewed as only one effort within California State Government to address the root causes of disparities that affect the system of IDD supports and services.

Root causes of inequities include intrapersonal, interpersonal, institutional, and systemic mechanisms that organize the distribution of power and resources differentially across lines of race, gender, class, sexual orientation, gender expression, disability, and other dimensions of individual and group identity.

2. Successes of the SAE Grant projects

“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”

Participants expressed that the SAE Grant projects have yielded a range of successes that collectively contribute to more accessible supports and services for persons with IDD and their families. They reported that SAE Grant projects have aimed at expanding expertise, ensuring that families receive personalized assistance that address their unique needs. CBOs outlined that collaboration, partnership, and strengthened community relationships have resulted in increased referrals, improved supports, and increased capacity of families to navigate the array of complex services. The provision of translation and interpretation services, bilingual staff capacity, and culturally relevant educational materials were reported to have contributed to bridging gaps and addressing disparities. Participants reported that SAE Grant projects employed a range of strategies, from one-on-one mentoring to virtual interactions to hosting conferences, designed to ensure that families have the resources and information they need. Of particular note were success stories that SAE Grant projects were asked to submit in annual reports to DDS. “Navigators or Navigator projects” were highlighted as shedding light on the challenges families face daily and providing direct assistance to help families overcome them. This project type was described as being successful in advocating for systemic change and informing future projects that could benefit persons with IDD and their families across diverse cultural and linguistic groups. Overall, participants underscored the significance of collaboration, cultural and linguistic competences, community engagement, and person-centered and family-centered approaches to project success.

Note: The NCCC-MA Team found that the capacity to measure and document decreases in disparities is closely linked to SAE Grant project type. Data from the Navigator and Promotora Programs analyzed in this report are consistent with the comments of Cultural Specialists participating in the listening sessions. However, increased capacity is needed within both with DDS and among SAE grantees to collect and report data that capture the extent to which programs affect POS and advance equity.

3. Barriers encountered in the SAE Grant projects

“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.”

Participants reported the implementation of SAE Grant projects has been hindered by a number of significant barriers. Participants described the short duration of the grant cycle as a serious obstacle to achieving sustainable, long-term change. Some of the barriers are centered on policies and practices within the IDD system and the fact that the socio-cultural contexts in which families live are not taken into consideration in service design and implementation. For example, participants described barriers related to accessibility, particularly when families require services outside of regular office hours, or when language accommodations are lacking. A recurring challenge is the struggle to attract and retain knowledgeable and skilled personnel due to low wages paid to direct support professionals and others within the field. The workforce shortage is further exacerbated by the need for personnel who can provide culturally and linguistically competent supports and services and work within underresourced communities. Ultimately, workforce shortages were viewed as affecting the accessibility, availability, acceptability, utilization, and quality of supports and services for the SAE Grant Program’s populations of focus. Another significant barrier described by CBOs was the lack of effective training for new service coordinators. According to participants,

the lack of effective training has resulted in incorrect responses and misinformation provided to families contributing to delayed access to services, and perpetuating distrust within the system. Moreover, CBOs cited limited access to technology adds another layer, particularly as some persons with IDD, families, and communities struggle to access virtual platforms effectively. Overall, participants highlighted a wide range of barriers.

Note: The barriers cited by CBOs are inherently embedded within California's system of supports and services for persons who experience IDD and their families — not only the SAE Grant Program. The NCCC-MA Team asserted that it is unrealistic to rely on one funded program to remedy the complex array of factors that contribute to the inequities that persons with IDD across the life course and their families experience in their day-to-lives. Moreover, most state developmental disabilities systems are dependent upon federal legislative authority including policies, regulations, and funding allocations that do not necessarily align with efforts to achieve equity.

4. Effectiveness of the SAE Grant projects in increasing equity

“Very effective. We have outreached to close to 1,000 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.”

Participants reported that the effectiveness of SAE Grant projects to increase equity span multiple dimensions. Participants cited education and self-efficacy of families as being particularly effective. Specifically, participants reported that by providing families with information and tools to navigate complex systems and develop advocacy skills, SAE projects support families to take control and access the services and supports they need. Participants stated that SAE Grant projects successfully engaged underserved and underresourced communities through focused outreach efforts. Participants underscored that when there are collaborative efforts among

service coordinators, CBOs, and Regional Centers, fostered an environment where families can feel understood and supported. While challenges remain, such as systemic limitations and resource constraints, the overarching sentiment from participants is that the SAE Grant projects have made progress in increasing equity.

Note: Overall data analysis completed by the NCCC-MA Team points to the fact that there is neither a shared definition/framework for equity among Regional Centers and other providers of supports and services nor within DDS and the California IDD system overall.

5. Effectiveness of the SAE Grant project in decreasing disparities

“Creating materials in Indigenous languages and explaining what certain IDD are in order for families to be educated Materials are not just fliers but also radio and FB live programming.”

Participants reported that the effectiveness of the SAE Grant projects in decreasing disparities was evident through the implementation of various strategies aimed at educating, empowering, and engaging underserved communities. Participants stated that by conducting outreach using culturally and linguistically competent approaches, SAE projects ensured that information is accessible, bridging the gap between historically underserved populations and the services they require. Participant stated that collaborative approaches helped build trust, improve partnerships, and ultimately identify and address barriers that contribute to disparities in access. While barriers remain, the overarching sentiment among participants was that SAE projects have been effective in making positive strides toward reducing disparities and ensuring that underserved and underresourced communities gain access to the services they need.

Note: The NCCC-MA Team found that the data necessary to document decreases in disparities in both administrative and project reports do not capture the extent to which these activities reported during the listening sessions affect POS.

6. Recommendations for improvement

“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”

CBO Recommendations for SAE Grant Program Improvement

Extend the duration of grants beyond one year. Longer funding periods, minimally two to three years, would provide organizations with the necessary time to plan, execute, and assess their initiatives, ultimately leading to more significant and sustained impact.
Simplify administrative processes and reporting requirements such as shifting from quarterly to biannual reports, could alleviate the burden.
Standardize reporting metrics to facilitate easier data comparison while also accommodating diverse SAE Grant projects.
Fund collaborative models and cross-project partnerships to foster synergistic efforts.
Participants reported that engaging the community's insights and involving marginalized voices were crucial.
Increase accountability within the overall SAE Grant Program. There is a need for comprehensive staff training, especially for service coordinators who are gatekeepers for services. Increased accountability mechanisms are needed for Regional Centers to ensure effective implementation of the overall SAE Grant Program and for individual grantees.
Offer opportunities for innovative funding allocation that supports community-generated ideas and prioritizes collaboration between agencies to spur transformative change within the system.

Overall, recommendations from the CBOs indicated that there is a call for extended grant cycles, streamlined processes, enhanced training, and innovative models.

In conclusion, the listening sessions with CBOs shed light on the status of the SAE Grant projects,

their implementation processes, successes, barriers, and effectiveness in increasing equity and reducing disparities. While SAE projects have established valuable community relationships, enhanced expertise, and supported families, the pressure to implement impactful changes within a limited timeframe undermine the capacity to establish lasting improvements.

Note: Substantive changes in the structure of the SAE Grant Program are necessary for CBOs to better accomplish project goals and objectives of increasing equity and reducing disparities for persons with IDD and their families.

Additional studies performed to validate recommended metrics, measures, and priorities for the SAE Grant Program

The NCCC-MA Team sought to provide further analysis to guide recommendations for metrics, measures, and priorities for the SAE Grant Program. Two additional studies were conducted. The first rated grantee annual progress reports to determine the extent to which progress and outcomes in reducing disparities and promoting equity were met and documented. The second is a triangulation report that explored the level of agreement among the different qualitative data findings. The summaries of these two studies are presented below. The comprehensive full report of Ratings of SAE Grant Project Annual Progress Reports is included in Attachment G, and the Triangulation of Qualitative Data is included in Appendix I.

Ratings of SAE Grant project annual progress reports

Regional Centers and CBOs that participated in the SAE Grant Program were required to submit quarterly and final project reports to DDS. Quarterly

reports documented the performed activities and project trajectory, and final reports described the projects' goals, objectives, performance measures, and outcomes.

The final reports included the following sections:

1. General Results Section

- a. A summary of activities that were implemented in the project (such as trainings, seminars, and community events) and the ways in which they impacted the project population.
- b. Top takeaway(s) and lesson(s) learned in reaching and engaging the project population and how this work generated new insights on the challenges and barriers families face in obtaining services and supports.
- c. Project success stories which included details about how the activities offered by the grant project had a positive effect on the lives of individuals with intellectual and developmental disabilities and their family members.

2. Successful and/or Innovative Strategies Section

- a. Descriptions of potential challenges in project implementation, in areas such as staff recruitment/hiring, staff turnover, participant attrition and service availability.
- b. Reports of collaborative efforts with other organizations.
- c. Details of how the grantee intended to apply what they learned from the project to their efforts to address disparities in services and supports in the future.
- d. Recommendations for future grant activities designed to reduce disparities.

Methods

The NCCC-MA Team reviewed the final reports for FY 18/19 and FY 19/20 as part of the independent evaluation process to explore what projects reported in terms of the progress made in addressing the identified disparities. Reports were provided by the Department of Disability Services. These reports were uploaded to Caspio™, an online cloud database platform, for ease of review and rating. The

results were then added to SPSS™ and frequency distributions were conducted. Sections 1a., 1b., 1c., and 2d, described above were used for the analysis. Goode's Disability Disparities Framework was used to rate the project reports and to answer the following question: To what extent do the projects report their progress or outcomes in reducing disparities or advancing equity in availability, accessibility, acceptability, quality and utilization?

In addition to these six factors of the framework, the success stories were reviewed to determine the extent to which they provided an example from the project which included results that were *transferable* for IDD disparities reduction and/or advancing equity across racial, ethnic, and linguistic groups.

Findings

There were 101 projects from FY 18/19 and FY 19/20 that were reviewed. However, of those projects, there were 16 reports that were not submitted (i.e., 13 Regional Center reports and three Community-Based Organization reports). There were 88 reports reviewed and rated (i.e., 35 reports for Regional Centers and 53 reports for CBOs) Results from the analysis of the Regional Center final reports revealed that, for all of the factors of the NCCC Disparities Framework, over 50% of the Regional Centers did not include documentation of progress or outcomes. The largest rating percentage was, 69%, which indicated that a large number of the reports did not document progress in addressing *quality* of supports and services. This was followed by lack of documentation of progress or outcomes for *utilization* at 66%. Almost half of the reports, 47% did report progress or outcomes on *availability* of supports and services. For the CBO ratings, the results were similar in that the largest rating percentage was 66%, which indicated that a large number of the reports did not document progress in addressing *quality* of supports and services. The lack of reporting of progress in *utilization* was almost even. For both Regional Centers and CBOs, transferability of the success stories was rated affirmatively for just over 40% of the reports.

Triangulation of qualitative data

As part of this project, a triangulation methodology was used to combine data from interviews, listening sessions, and qualitative survey responses.

Triangulation is defined as combining multiple methods to study the same phenomenon.⁵⁰ For this project, data from interviews, listening sessions, and the qualitative responses to the CBO 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:

- 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;⁵¹
- Providing multi-faceted understanding – where the data completeness and/or confirmation is viewed by considering the findings across the various sources of data;⁵² and
- 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).⁵⁰

For these and other reasons, triangulation can increase the validity of research results⁵³.

Methods

Two triangulation methods as proposed by Briller et al.⁵² were used – methodological triangulation using multiple data collection strategies and data triangulation using information from different respondent types. 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, SAE project managers, Cultural Specialists of the Regional Centers, CBO staff, DDS staff, and family members of persons with intellectual and developmental disabilities.

Findings

Four themes were revealed during the triangulation process.

- **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.*** Within the data collected from both families and SAE personnel, there was agreement that efforts had been made to increase access to linguistically competent services including translation and interpretation. Those families participating in the self-determination program felt it helped them receive services that met their needs in a greater way. Some families felt there was a need to increase the number of staff and providers of color.
- **Theme 2: *SAE grantees have already initiated efforts in addressing some inequities, but more is needed.*** The triangulation process revealed agreement by families, DDS staff, and SAE personnel that the SAE Grants were helping RCs make progress towards addressing disparities. Families highlighted ongoing issues such as inequities in the services available to individuals from diverse groups.
- **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.*** Additionally, they felt providers need increased capacity so families can access services once they are approved to receive them. 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.
- **Theme 4: *Services and supports should be designed and allocated through the lens of family members as empowered advocates.*** Family members, DDS staff, and SAE personnel all expressed a desire for service recipients to receive resources to meet their needs, interests, and desired quality of life. When trying to achieve this goal, family members felt they had to overcome unnecessary barriers and gatekeeping efforts. A similar observation was shared by both DDS staff and SAE personnel who acknowledged areas in which internal practices and procedures

contributed to families not accessing services at greater levels. SAE personnel and families were in agreement that another factor was a lack of knowledge by families on how to navigate the RCs' complex systems and procedures.

Recommendations

The NCCC-MA Team strongly recommends continued funding for the SAE Grant Program as well as policy and structural changes to ensure the program fulfills its legislative to advance equity. The SAE Grant Program is an innovative and essential aspect of California's system of supports and services for persons who experience IDD and their families. The grant program invests dedicated attention and critical resources to identify and mitigate disparities that disproportionately affect specific racial, ethnic, and linguistic populations and underresourced communities.

As previously delineated in this report, the three stated deliverables in the RFP HD219056 and corresponding objectives and sub-objectives that the NCCC-MA Team used to conduct this independent evaluation overlap — each is dependent on data collection and analysis processes to recommend metrics, measures, and priorities for the SAE Grant Program. This included (1) data collection and analyses methods and processes to assess the efficacy of the program; (2) recommendations for quantitative and qualitative measures and metrics based on current evidence, promising practices, change theory models, and other relevant factors; and (3) approaches to prioritize areas of focus, populations, interventions, and modification to the structure of the SAE Grant Program.

The NCCC-MA Team puts forth the following recommendations that are grouped into four categories —

1. Grant focus,
2. Project structure,
3. Project types, and
4. Grant measures.

1. Grant focus

DDS offered an extensive array of key priority areas for the 2022-2023 SAE Grant Program. Careful consideration should be given to reducing the number of priorities by identifying areas of impact that have the greatest likelihood of reducing disparities and increasing access for the racial, ethnic, and linguistic populations of focus. DDS is commended for its statewide engagement of key constituency groups to elicit priority areas of focus. However, many of the priority areas will not lead to measurable short, intermediate, or even long-term disparities reduction and increases POS as defined by legislation. This does not imply that the current areas of focus are not important to IDD supports and services, rather they may not result in outcomes aligned with the SAE Grant Program's vision as currently stated in the 2022-2023 guidelines.⁵⁴

2. Project structure

Define what equity is within DDS and the SAE Grant Program

Developmental Disabilities systems nationally lag far behind in defining the concept of equity, how to measure efforts to achieve equity across the complex array of supports and services within these systems, and how to partner with communities, populations, and families disproportionately affected by inequities. Data collected for this evaluation indicates that DDS has not yet established a shared definition and framework for advancing equity, nor is this concept well understood within the service provider network and among key constituency groups in the state. While disparities reduction and equity are related, they are not the same. The grant program and guidance must provide clarity going forward to ensure consistency and integrity across applicants and funded grantees. Currently the program relies almost exclusively upon POS as a measure of service access *and* equity.

Establish a requirement that SAE Grants will be awarded to Regional Centers if they partner with a community-based organization

Since equitable service is stated by DDS in its vision, revisiting how resources are distributed within the SAE Grant Program to actually advance equity should be a strong consideration. This approach benefits CBOs and Regional Centers by adhering to two National Center for Cultural Competence principles of community engagement: (1) Communities should economically benefit from collaboration; and (2) Community engagement should result in the reciprocal transfer of knowledge and skills among all collaborators and partners.⁴¹

Refine the focus on disparities reduction

The structure of the current SAE Grant Program and guidance are largely based on disparity populations defined by race, ethnicity, and languages spoken. Since disparities are the product of inequities, it is important that the SAE Grant Program is structured to respond to the question – *Disparities in what?* Using a disparities framework that is available in the published literature – enables DDS and grantees to discern if there is a disparity in availability of supports and services, accessibility of supports and services, acceptability of supports and services, quality of supports and services, and utilization of supports and services. Using a nuanced approach will enhance the capacity of grantees to be more effective in their disparities reduction interventions and to measure impact and outcomes over time.^{18,41,55} For example, to what extent is the SAE Grant Program designed to reduce disparities at the individual (person with lived experience of IDD), family, community, organizational, and systems levels?

Make better use of the current evidence in disparities reduction including requiring cultural and linguistic competence

The SAE Grant guidance should require that culturally competent and linguistically competent practices are embedded throughout each project. Cultural competence and linguistic competence are evidence-based practices that reduce disparities. Grantee applicants should be required to define cultural competence and linguistic competence and how such practices will be applied in their projects. Simply stating cultural and linguistic competence is inadequate to determine if such practices are actually being used and evaluated for their effectiveness.

Increase the length of time that SAE Grant projects are funded linked to community accountability and performance

Current evidence in other fields clearly indicates that disparities reduction is a developmental process that occurs over time and not in 1-2 year intervals as the SAE Grant Program is currently structured. Longer-term focused implementation and evaluation of grants areas that have the greatest likelihood or track record of reducing disparities will be important going forward. Strongly consider awarding one-year planning grants with up to three-four years of additional funding based on: (1) the extent to which communities are actively engaged in the planning process to ensure their interests and needs are met; and (2) adherence to revised grantee performance and accountability measures. As stated previously, it should be noted that DDS began implementing this recommendation by expanding awards up to 24 months in the 2023-2024 grant cycle.

Require a logic model and a theory of change framework for all SAE Grant projects

DDS should provide a logic model that instructs grantee applicants on how to graphically depict

the relationships among the resources, activities, outputs, outcomes, and impact of the SAE Grant Program and proposed projects. Data collected by the NCCC-MA Team indicated that neither the Regional Centers nor the CBOs used logic models which are proven effective tools to assist in program planning, implementation, management, evaluation, and reporting.⁵⁶ Additionally grant applicants should be encouraged to use a theory of change framework, which entails a comprehensive description and illustration of how and why a desired change is expected to happen in a particular context.⁴⁴

Develop more effective measures and evaluation methodologies to assess the SAE Grant Program

Begin a process starting with 2023-2024 grant guidance to require and support measures to more effectively document the outcomes and impact of the SAE Grant Program. This may include but is not limited to: (1) identifying quantitative and qualitative measures and metrics that document disparities reduction at the individual (person with lived experience of IDD across the life course); (2) requiring grantees to collect and report data that demonstrate impact and outcomes that do not solely rely on POS; and (3) assuring the meaningful participation of constituency groups involved/served by the grant projects in community-engaged, culturally and linguistically responsive evaluation processes to elicit their experiences. Evaluation data collected thus far indicate that both Regional Centers and CBOs will require technical assistance to improve their capacity to collect data, analyze, and report data for SAE projects.

Begin a process to define and develop measures for equity in IDD services and supports. The primary measure to evaluate and demonstrate the efficacy of the SAE Grant Program is POS. While POS is a solid measure of who is accessing services by race, ethnicity, and language – it should not be the sole measure because what persons with IDD need and prefer in terms of supports and services change over time from infancy through old age. Given this, there will always be disparities in expenditures based on numerous factors. The current POS measure does not discern root causes and if persons with IDD

(across the life course) are actually getting what they want and need to be fully included in all aspects of community life. Moreover, POS only tracks who is in the system not those who may be discouraged because the services and supports are not available, accessible, acceptable, and of high quality to them – thereby affecting utilization and ultimately POS.

3. Project types

As stated previously, careful consideration should be given to reducing the number of priorities by identifying areas of impact that have the greatest likelihood of reducing disparities and increasing access for the racial, ethnic, and linguistic populations of focus. Continue to fund project types as pilots to identify promising practices. The NCCC-MA Team offers suggestions for the four project types currently listed in SAE Grant guidance at the time the evaluation was conducted.

DDS description of project types for the 2018–2019 and 2019–2020 grant years

i. Education and training

Increase self-advocate/family knowledge about topics relating to service access, the Regional Center system, leadership development, business development, advocacy, independent facilitation, implicit bias, and developmental disabilities.

Recommendations education and training

The provision of education and training may not result in meaningful increase in POS, particularly in the short-term. Regional Centers and CBOs would need to prove the direct correlation between a training, advocacy, leadership, or business development activity and an increase in service access or disparities reduction (i.e., logic model, theory of change, data collection including ongoing and longer-term follow-up with participants, data analysis and reporting). As stated previously, Regional Centers and CBOs requested more clarity in the data they collect and technical assistance and support to build their capacity.

These education and training activities are an important resource to persons who experience IDD and their families as well as CBOs. **The NCCC-MA Team suggests that DDS should continue to fund this project type but it should not be subjected to the stringent metric of POS due to the complexity and cost associated with proving outcomes and impacts by race, ethnicity, and language based solely on expenditures for previously stated reasons.** If the project type continues to include staff training, emphasis should be placed on ensuring supports and services are culturally and linguistically competent particularly for the populations of focus disproportionately affected by disparities (i.e., availability, accessibility, acceptability, quality, and utilization). If the project type continues to include families, emphasis should be placed on ensuring support to assist families navigate the complex DDS system (from awareness, eligibility determination, complaint and dispute resolution processes, service selection and use, and providing feedback through evaluation). Using an equity lens, encourage and fund projects that hire families as navigators.

ii. Engagement and outreach

Increase community awareness and engagement through outreach activities (e.g., informational presentations, fairs, developmental screening events).

Recommendations engagement and outreach

Community engagement and outreach are essential to inform culturally and linguistically diverse families and communities about DDS supports and services throughout the life course. The NCCC-MA Team suggests continuing to fund this project type. Similar to Education and Training, this project type may not yield the data required to satisfy POS. Again, grantees will need to be able to demonstrate a direct correlation between the activities (informational presentations and fairs) that resulted in increased service access or a reduction in disparities.

Developmental screening events have more promise, yet the same organizational capacity will be required — to collect and track data from families to determine if children were determined

eligible and actually received supports and services. It will be necessary to differentiate project requirements because Regional Centers have different responsibilities and resources when compared to CBOs. Another reason to require partnerships between Regional Centers and CBOs for the SAE Grant Program.

iii. Community Connector

Utilize community leaders, family members, and self-advocates to provide individualized support to assist families with accessing services. Promotora, Navigator, Peer/Parent Mentor or Independent Facilitator are examples of community connector projects.

Recommendations Community Connector

The NCCC-MA Team supports continued funding of this project type. Priority funding should be given to those racial, ethnic, and linguistic groups (i.e., monolingual in languages other than English, limited English proficiency as defined by US Census, ASL or other sign language users) that experience the greatest percentage of disparities in service access. While the demographic make-up may indicate a larger population of a particular racial or ethnic group, smaller population groups may be inadvertently overlooked. This project type should require Regional Centers to partner with CBOs.

iv. Workforce capacity and development

Diversify and increase cultural and linguistic competency of Regional Center and/or service provider staff, expand available workforce, and promote business ownership from diverse communities.

Recommendations capacity and development

Should DDS continue to fund this project type, innovative, collaborative, and strategic approaches will be required. Clear guidance should be provided on exactly what cultural competence and linguistic competence mean for individuals (various workforce disciplines including direct support professionals) and organizations (policy and practice). There is not a shared understanding across Regional Centers and CBOs: 1) of what cultural competence

and linguistic competence are, 2) of how these practices are defined and conceptualized differently, and 3) that cultural and linguistic are not synonymous with language access. Expanding the available workforce is a long-term goal given the crisis in the number of direct support professionals who have left the service system, particularly after the onset of the COVID-19 pandemic, and for other reasons including wages and working conditions. Consideration should be given to whether or not this area of focus is the most appropriate investment for DDS grant funds.

The NCCC-MA Team offers the following recommendations if DDS continues to offer this project type for the SAE Grant Program.

- Collaborate with universities and colleges for practicum experiences with an emphasis on students from the identified racial, ethnic, and linguistic groups in the legislation. Consider loan repayment or other incentives for disciplines such as psychology, speech and language pathology, physical therapy, occupational therapy, early intervention, and nursing.
- Collaborate with communities to increase awareness of the need for respite care providers from underresourced communities and racial, ethnic, and linguistic groups identified by SAE legislation.
- Collaborate with the State's small business administration to leverage resources and support business ownership from the racial, ethnic, and linguistic groups identified by SAE legislation.
- Conduct a national study of successful recruitment and retention of disability professionals (including direct support personnel).

4. Grant measures

All projects are required to report data to show progress and outcomes of activities. Projects may provide quantitative or qualitative data, or both.

Quantitative data

Quantitative data can be measured, such as the number of participants in Community Connector program, pre/post surveys that are scored with numbers, and comparison of POS expenditures before and after participation in a project.

- As indicated previously, more effective measures and evaluation methodologies are needed to document the impact of the SAE Grant Program. DDS or a DDS contractor is needed to provide technical assistance to Regional Centers and CBOs to increase their capacity for effective data collection, analysis, and reporting. Grant applicants and grantees should be required to have a logic model, a theory of change framework, and other capacities described on page 22.
- The NCCC-MA Team recommends that DDS include an outcome measurement system based on a DDS logic model and proposed theory of change, for cross-project analysis. This may include changes in awareness and knowledge, increased service use by underserved communities, and improved availability, accessibility, acceptability, quality, and utilization. These data could be collected from SAE Grant Program participants first with a baseline survey and then annually and entered by funded projects in a DDS portal.
 - » Number
 - » Milestone
 - » Percentage
 - » Percentage increase
 - » Data could also be collected on the extent to which there were changes in disparities reduction at the individual, family, community, organizational, or system levels.
- DDS should define the minimal data set expected from quantitative outcomes. Comparing POS expenditures before and after participating in a project is dependent upon the nature of the

project or project type. There are multiple factors that could affect the expenditures (“n”) for POS.

- Where projects are working intensively with specific persons who experience IDD or families receiving DDS services, consideration should be given to collecting UCIs or similar identifiers and to obtain permission from families for data sharing. This would allow outcomes to be tracked in existing data rather than expecting specific types of data collection from the SAE grantees.
- Data collection from grantees could focus on meeting the terms of the awards such as the number of people served. It would be helpful to also have a measure of intensity including but not limited to:
 - » In what capacity are grantees interacting with persons with IDD and/or with families?
 - » How often are grantees interacting with persons with IDD and/or families?
 - » How many hours are grantees delivering to persons with IDD and/or their families?
- Gathering these data may provide information on “dosing” that may inform promising practices for disparities reductions.
- DDS should give consideration to identifying a small number of measures that are appropriate for the project types. These measures should be required in order for the SAE project to be easily compared and aggregated.

progress and efforts taken to mitigate challenges and the results. This can provide a rich source of information to assist other grantees.

- Current guidance requests that SAE grantees submit a “success story.” This reporting requirement provides SAE grantees the opportunity to showcase or highlight one person with IDD, family, staff member, or other effort. However, it does not examine the extent to which the “success story” is generalizable to other persons, situations, and settings. The NCCC-MA Team assessed generalizability in the grantee reports submitted to DDS as one measure of outcomes.
- DDS should consider requiring SAE grantees or an independent entity to conduct focus groups, convene listening sessions, or otherwise query project participants to gather in-depth information regarding whether the Regional Center or CBO improved the availability, accessibility, acceptability, quality, and utilization of supports and services — as applicable to the specific project.

Qualitative data

Qualitative data is a description, such as what participants say they learned in an orientation. Qualitative data is used to gain an understanding of underlying reasons and motivations and uncover trends in thoughts and opinions. Qualitative data may be collected using open-ended written or verbal questions in surveys, focus groups, and interviews. Findings from qualitative data are typically summarized in writing.

- All qualitative data collection and reporting should be linked to the DDS logic model and proposed theory of change for each SAE grantee as described on page 18-23. Consider amending DDS reporting guidance to require SAE grantees to describe in detail challenges that impeded

Conclusion

The Director of the Georgetown University National Center for Cultural Competence (NCCC), and Principal Investigator for this independent evaluation, testified before the California State Legislature on April 26, 2023. Three salient areas of focus from the testimony merit emphasis in this final report.

About Equity...

Developmental Disabilities systems nationally lag far behind in defining the concept of equity, how to measure efforts to achieve equity across the complex array of supports and services within these systems, and how to partner with communities, populations, and families disproportionately affected by inequities. It is important to note that the SAE Grant Program has been successful in advancing equity in several ways. First, the insight from DDS and a subsequent amendment to legislation which made SAE Grant funds available to CBOs is a huge step toward equity. CBOs otherwise would not have directly benefited from these fiscal resources and the opportunity to demonstrate the deep knowledge they have of their communities and ways to partner in disparities reduction efforts. This policy is consistent with two NCCC guiding values and principles that advance equity.

Communities should economically benefit from collaboration.

Community engagement should result in the reciprocal transfer of knowledge and skills among all collaborators and partners.

Revisiting Purchase of Services (POS)

The primary measure to evaluate and demonstrate the efficacy of the SAE Grant Program has been POS. While POS is a solid measure of who is accessing services by race, ethnicity, and language – it should not be the sole measure of success and impact because what persons with intellectual and developmental disabilities need and prefer in terms of supports and services change over time from

infancy through old age. Given this, there will always be disparities in expenditures based on numerous factors. The current POS measure does not discern root causes and if persons with intellectual and developmental disabilities (across the life course) are actually getting what they want and need to be fully included in all aspects of community life. Moreover, POS only tracks who is in the system not those who may be discouraged because the services and supports are not available, accessible, and acceptable to them – thereby affecting utilization.

Aligning policy and the evidence about disparities reduction

Current evidence in other fields clearly indicates that disparities reduction is a developmental process that occurs over time and not in one-two year intervals as the SAE Grant Program is currently structured – which may be attributed to and the result of state budgeting policy. Longer-term focused implementation of project types that have the greatest likelihood or track record of reducing disparities will be important going forward. Additionally, in support of advancing equity, some of the project types should continue to include community engagement and parent education. The metrics and outcomes for these projects should be adjusted to their purposes – these grant areas will help build trust and knowledge within communities, and over time this will lead to disparities reduction, beyond Purchase of Services.

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Attachment A

Structured Interview Questions: Regional Center Directors & Service Access and Equity Project Managers

Structured Interviews

Regional Center Directors & Service Access and Equity Project Managers

1. Demographics
 - a. Years in Role/current position
2. Can you describe the racial, ethnic, and linguistic disparities among people with intellectual and developmental disabilities (IDD) in your region?
 - a. Yes, (please describe)
 - b. No
3. How would you describe 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?
4. What is the current status of disparities in Purchase of Services among the racial, ethnic, and linguistically diverse populations supported by your Regional Center?
5. Why did your Regional Center decide to submit a proposal to DDS for its Service Access and Equity (SAE) program? What is/was your area of focus and designated disparity population(s)? Is this project expanding capacity or is it new work?
6. How does your Regional Center define equity for persons with IDD and their families? How was this definition used in your overall grant project?
7. How was your project designed to mitigate disparities at the following levels? (Choose all that apply)
 - a. Individual
 - b. Family
 - c. Community
 - d. Organizational
 - e. Systems
8. Were culturally competent approaches used to implement the grant specifically in supports, services, and project activities?
 - a. Yes (please describe)
 - b. No (why not?)
 - c. N/A
 - d. Don't know

Structured Interviews: Regional Center Directors & Service Access and Equity Project Managers (Cont'd)

9. Were linguistically competent approaches used to implement the grant specifically in supports, services, and project activities?
 - a. Yes, (please describe)
 - b. No
 - c. N/A
 - d. Don't know
10. Did your Regional Center use a theory of change framework for your grant project?

- a. Yes (describe the change theory)
- b. No, (why not?)
- c. Don't know

A theory of change is a comprehensive description and illustration of how and why desired change is expected to happen in a particular context).

11. Did your Regional Center use a logic model to demonstrate the correlation between advancing equity and disparities reduction within your grant project?
- a. Yes (please describe logic model)
 - b. No, (why not?)
 - c. Don't know

A logic model is a visual way to illustrate the resources or inputs required to implement a program, the activities and outputs of a program, and the desired program outcomes (short-term, intermediate and long-term).

12. Did you engage persons with IDD and their families to evaluate supports and services provided by your Service Access and Equity (SAE) grant project?
- a. Yes, (please describe)
 - b. No, (why not?)
 - c. N/A
 - d. Don't know.
13. What have you found to be the most significant challenges in implementing your SAE Grant project?
14. Did your SAE project work directly with persons with intellectual and developmental disabilities and their family members from racially, ethnically, culturally and linguistically diverse backgrounds?
- a. Yes, If yes, what barriers were encountered in these efforts?
 - b. No, (why not?)
 - c. N/A
 - d. Don't know

Structured Interviews: Regional Center Directors & Service Access and Equity Project Managers (Cont'd)

15. What is the most significant outcome from your SAE project in terms of disparity reductions?
16. What data did you collect to document disparities reductions?
17. Did you collect and analyze data on SAE project findings by each of the following?
- a. Race
 - b. Yes, (please describe)
 - i. No, (why not?)
 - ii. N/A
 - iii. Don't know
 - c. Ethnicity
 - i. Yes, (please describe)
 - ii. No, (why not?)
 - iii. N/A
 - iv. Don't know
 - d. Languages spoken
 - i. Yes, (please describe)
 - ii. No, (why not?)
 - iii. N/A

- iv. Don't know
 - e. SES
 - i. Yes, (please describe)
 - ii. No, (why not?)
 - iii. N/A
 - iv. Don't know
 - f. Geographic locale
 - i. Yes, (please describe)
 - ii. No, (why not?)
 - iii. N/A
 - iv. Don't know
 - g. Other factors
 - i. Yes, (please describe)
 - ii. No, (why not?)
 - iii. N/A
 - iv. Don't know
- 18. What is your current capacity for collecting, analyzing and reporting on disparities data for the SAE program? Please explain your answer.
 - a. High capacity
 - b. Moderate capacity
 - c. Low capacity
 - d. No capacity

Structured Interviews: Regional Center Directors & Service Access and Equity Project Managers (Cont'd)

- 19. Did your project increase:(Note: Prompt regarding the populations of focus, if necessary)?
 - a. Availability of supports and services
 - i. Yes, (please describe)
 - ii. No
 - iii. N/A
 - iv. Don't know
 - b. Accessibility of supports and services
 - i. Yes, (please describe)
 - ii. No
 - iii. N/A
 - iv. Don't know
 - c. Acceptability of supports and services
 - i. Yes, (please describe)
 - ii. No
 - iii. N/A
 - iv. Don't know
 - d. Quality of supports and services
 - i. Yes, (please describe)
 - ii. No
 - iii. N/A
 - iv. Don't know
 - e. Utilization of supports and services
 - i. Yes, (please describe)
 - ii. No
 - iii. N/A

iv. Don't know

20. Within your SAE Grant activities, what strategies were used to reach potential individuals with IDD and their families that are unknown or not receiving services through the Regional Center?
 - a. In what ways did the strategies used result in new individuals from diverse racial, ethnic and linguistic backgrounds accessing services?
21. 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?

Attachment B

Structured Interview Questions: Department of Developmental Services Staff

Structured Interviews Department of Developmental Services Staff

1. There are many definitions of equity in general and in human services in particular. How does Department of Developmental Services (DDS) define equity?
2. How would you describe DDS's vision to achieve equity?
3. How would you describe the role of disparities reduction in achieving equity in California's developmental disabilities system?
4. How would you describe 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?
5. How would you describe the overall impact of the Service Access and Equity (SAE) grant program in reducing these disparities?
6. To what extent do purchase of service expenditures accurately identify disparities between racially, ethnically and linguistically diverse populations served by DDS?
7. What theory of change models are used by DDS to facilitate disparities reduction in the SAE Grant Program?
8. To what extent is the SAE Grant Program designed to reduce disparities at the following levels:
 - a. Individual?
 - b. Family?
 - c. Community?
 - d. Organizational?
 - e. Systems?
9. What is the logic model that the department used for disparities reduction at each of the previously identified levels? (Individual, family, community, organizational, system)
10. To what extent does DDS differentiate disparities reduction using the following categories?
 - a. Availability
 - b. Accessibility
 - c. Acceptability
 - d. Quality
 - e. Utilization

11. What measures are employed by DDS to document the extent to which SAE grantees use culturally competent approaches in:
 - a. Translation (equipment, translator services, translating brochures or materials, etc.)
 - b. Outreach (community events, website or social media design, materials, etc.)
 - c. Workforce capacity (staff training, incentives for bilingual employees, etc.)
 - d. Parent education (online or in person trainings, workshops, etc.)
 - e. Promotora (Peers educating community members about accessing RC services)
 - f. Family/ consumer support services (1:1 coaching, enhanced case management, service navigation, etc.)
12. What measures are employed by DDS to document the extent to which SAE grantees use linguistically competent approaches in:
 - a. Translation (equipment, translator services, translating brochures or materials, etc.)
 - b. Outreach (community events, website or social media design, materials, etc.)
 - c. Workforce capacity (staff training, incentives for bilingual employees, etc.)
 - d. Parent education (online or in person trainings, workshops, etc.)
 - e. Promotora (Peers educating community members about accessing RC services)
 - f. Family/ consumer support services (1:1 coaching, enhanced case management, service navigation, etc.)
13. There is considerable evidence that disparities reduction, like cultural competence, is a developmental process that occurs over time and not in 1–2-year increments. How was this factor taken into consideration in the design of the SAE Grant Program?
14. How feasible is it for DDS to restructure approaches and components of the Service Access and Equity grant program based on what is learned from this evaluation?
15. What have you found to be the most significant challenges in **implementing** the SAE Grant Program?
16. What have you found to be the most significant challenges in **evaluating** the SAE Grant Program?
17. In addition to the SAE Grant Program, what other efforts is the department undertaking (including other organizations that you are working with) to:
 - a. Increase equity
 - b. Decrease disparities
18. It must be recognized and accepted that some of the contributing or causal factors for disparities in developmental disabilities supports and services are neither under the auspices nor control of California Department of Developmental Services. What are the disparities that are outside of Department's control that impact persons with IDD and their families from racially, ethnically, culturally, and linguistically diverse groups?

Attachment C

Listening Session Questions: Cultural Specialists

Listening Session Cultural Specialists

1. What region are you representing?
2. How long have you been a Cultural Specialist at the Regional Center?
3. How does your Regional Center define equity for the population of people with intellectual and developmental (IDD) and their families?
4. How would you describe the root causes or factors that contribute to disparities in California's system for persons with IDD and their family members from racially, ethnically, culturally, and linguistically diverse backgrounds?
5. What do you view as the role of the Cultural Specialist in disparities reduction in the California IDD system?
6. How have you been involved in the Service Access and Equity (SAE) grant program in your Regional Center?
7. What recommendations do you have for DDS about disparities reduction?

Attachment D

Listening Session Questions: Community Based Organizations (CBOs)

Listening Session Community Based Organizations (CBOs)

1. How would you describe 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 backgrounds?
2. List up to three successes achieved by your Service Access and Equity (SAE) grant project.
3. List up to three barriers encountered in implementing your SAE Grant project.
4. How would you describe the effectiveness of your SAE Grant project in?
 - a. Increasing equity?
 - b. Decreasing disparities?
5. Thinking of the statewide SAE Grant Program, what two recommendations for quality improvement would you suggest to the Department of Developmental Disabilities Services?

Attachment E

Survey Questions: Community Based Organizations (CBOs)

Survey Community Based Organizations (CBOs)

Demographics

- a. What is the name of your organization?
 - b. What is your current role/position?
 - c. How many years have you been in this role/position?
 - d. In what region is your community-based organization located?
 - e. Do you have more than one Service Access and Equity (SAE) projects? If yes, how many?
 - f. What is the name of your SAE project?
 - g. What is the population focus for your SAE project(s)?
 - h. How many years of funding have you received for your SAE project(s)?
 - i. In which cycle were you funded: (check all that apply)
 - i. FY 18/19
 - ii. FY 19/20
 - iii. FY 20/21
 - iv. FY 20/22
1. Why did your organization decide to submit a proposal to DDS for its SAE program? Is this project expanding capacity or is it new work?
 2. How was your project designed to reduce disparities at the following levels?
 - a. Individual level
 - b. Family level
 - c. Community level
 - d. Organizational level
 - e. Systems level
 3. Were culturally competent approaches used to implement the grant specifically in supports, services, and project activities?
 - a. Yes (please describe)
 - b. No (why not?)
 - c. N/A
 - d. Don't know
 4. Were linguistically competent approaches used to implement the grant specifically in supports, services, and project activities?
 - a. Yes, (please describe)
 - b. No (why not?)
 - c. N/A
 - d. Don't know
 5. Did your organization use a theory of change framework for your SAE Grant project?
 - a. Yes (describe the change theory)
 - b. No (why not?)
 - c. Don't know

A theory of change is a comprehensive description and illustration of how and why desired change is expected to happen in a particular context)

6. Did your organization use a logic model to demonstrate the correlation between advancing equity and disparities reduction within your grant project?
 - a. Yes (describe the logic model)
 - b. No (why not?)
 - c. Don't know

A logic model is a visual way to illustrate the resources or inputs required to implement a program, the activities and outputs of a program, and the desired program outcomes (short-term, intermediate and long-term).

7. Did you engage persons with intellectual and developmental disabilities (IDD) and their families to evaluate supports and services provided by your SAE Grant project?
 - a. Yes, (please describe)
 - b. No, (why not?)
 - c. N/A
 - d. Don't know
8. What have you found to be the most significant challenges in implementing your SAE Grant project?
9. Did your SAE Grant project work directly with persons with IDD and their family members from racially, ethnically, culturally and linguistically diverse backgrounds?
 - a. Yes, (please describe the barriers that were encountered in these efforts)
 - b. No, (why not?)
 - c. N/A
 - d. Don't know
10. What is the most significant outcome from your SAE Grant project in terms of disparity reductions?
11. What data did you collect to document disparities reductions resulting from your SAE Grant project?
12. Did you collect and analyze data on project findings by each of the following?
 - a. Race
 - i. Yes, (please describe)
 - ii. No, (why not?)
 - iii. N/A
 - iv. Don't know
 - b. Ethnicity
 - i. Yes, (please describe)
 - ii. No, (why not?)
 - iii. N/A
 - iv. Don't know
 - c. Languages spoken
 - i. Yes, (please describe)
 - ii. No, (why not?)
 - iii. N/A
 - iv. Don't know
 - d. SES
 - i. Yes, (please describe)
 - ii. No, (why not?)
 - iii. N/A
 - iv. Don't know
 - e. Geographic locale
 - i. Yes, (please describe)

- ii. No, (why not?)
 - iii. N/A
 - iv. Don't know
 - f. Other factors
 - i. Yes, (please describe)
 - ii. No, (why not?)
 - iii. N/A
 - iv. Don't know
- 13. What is your current capacity for collecting, analyzing and reporting on disparities data for the SAE Grant project?
 - a. High capacity
 - b. Moderate capacity
 - c. Low capacity
 - d. No capacity
- 14. Did your SAE Grant project increase:
 - a. **Availability** of supports and services (i.e., the array, type, and intensity)
 - i. Yes, (please describe)
 - ii. No
 - iii. N/A
 - iv. Don't know
 - b. **Accessibility** of supports and services (i.e., geographic distribution, hours of delivery, technology, language access, accommodations, and universal design)
 - i. Yes, (please describe)
 - ii. No
 - iii. N/A
 - iv. Don't know
 - c. **Acceptability** of supports and services (i.e., system capacity to plan, deliver, and evaluate culturally and linguistically competent supports and services to diverse populations across the life course)?
 - i. Yes, (please describe)
 - ii. No
 - iii. N/A
 - iv. Don't know
 - d. **Quality** of supports and services (i.e., the totality of features and characteristics of supports and services that enable systems and organizations to be responsive to and satisfy the interests and needs of a given population)
 - i. Yes, (please describe)
 - ii. No
 - iii. N/A
 - iv. Don't know
 - e. **Utilization** of supports and services (i.e., utilization rates across culturally and linguistically diverse populations)
 - i. Yes, (please describe)
 - ii. No
 - iii. N/A
 - iv. Don't know
- 15. There are persons with IDD and their families that are either unknown or not receiving services through the Regional Center? What strategies were used to reach these individuals and their families? Indicate if not applicable to your SAE Grant project.
- 16. In what ways did the strategies used result in new individuals and families from diverse racial, ethnic

and linguistic backgrounds accessing services?

17. How important is the grant program to your organization's efforts to decrease disparities among persons with IDD across racial, ethnic and linguistic groups?
18. How would you describe 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 backgrounds?
19. List up to three successes achieved by your Service Access and Equity (SAE) grant project.
20. List up to three barriers encountered in implementing your SAE Grant project.
21. How would you describe the effectiveness of your SAE Grant project in?
 - a. Increasing equity?
 - b. Decreasing disparities?
22. Thinking of the statewide SAE Grant Program, what two recommendations for quality improvement would you suggest to the Department of Developmental Disabilities Services?

Attachment F

Listening Session Questions: Families of Persons who Experience Intellectual and Developmental Disabilities (IDD)

Listening Session

Families of Persons who Experience Intellectual and Developmental Disabilities (IDD)

1. Were the supports and services you received **available**:
 - a. When you and your family needed them?
 - b. In your preferred language?
 - c. In ways that took your family's culture into consideration?
2. Were the supports and services **accessible** (easy to get to or find) when you needed them?
3. How acceptable were the supports and services you received?
 - Very acceptable
 - Acceptable
 - Somewhat acceptable
 - Not acceptable all
 - Please tell us why you selected that rating.
4. How would you rate the **quality** of the supports and services you received?
 - Excellent
 - Good
 - Fair
 - Poor

Please tell us why you selected that rating.

5. Did you use the supports and services that were offered to you and your family member?
 - Yes or No (Why or why not)
6. How useful were the supports and services you received?
 - Very useful
 - Useful
 - Somewhat useful
 - Not too useful
 - Not useful at all
 - Please tell us why you selected that rating.
7. Based on your own experience, would you recommend the supports and services provided through Regional Centers to another family?
 - Yes or No
 - If yes, why?
 - If no, why not?
8. What recommendations would you make to the Department of Disability Services (DDS) to improve supports and services for persons with developmental disabilities?

Attachment G

Ratings of SAE Grant Project Annual Progress Reports

Ratings of SAE Grant Project Annual Progress Reports

Introduction

Regional Centers and Community Based Organizations (CBOs) that participated in the Service Access and Equity (SAE) grant program were required to submit quarterly and final project reports to the Department of Disability Services. Quarterly reports documented the performed activities and project trajectory. These were due on the last day of the month following the end of each quarter. Grantees were also required to write and submit a final report within forty-five days of the project end date. The final reports described the projects' goals, objectives, performance measures, and outcomes.

The final reports included the following sections:

1. General Results Section:

- a. A summary of activities that were implemented in the project (such as trainings, seminars, and community events) and the ways in which they impacted the project population.
- b. Top takeaway(s) and lesson(s) learned in reaching and engaging the project population and how this work generated new insights on the challenges and barriers families face in obtaining services and supports.
- c. Project success stories which included details about how the activities offered by the grant project had a positive effect on the lives of individuals with intellectual and developmental disabilities and their family members.

2. Successful and/or Innovative Strategies Section:

- d. Descriptions of potential challenges in project implementation, in areas such as staff recruitment/hiring, staff turnover, participant attrition and service availability.
- e. Reports of collaborative efforts with other organizations.

- f. Details of how the grantee intended to apply what they learned from the project to their efforts to address disparities in services and supports in the future.
- g. Recommendations for future grant activities designed to reduce disparities.

Methods

The NCCC reviewed the final reports for FY 18/19 and FY 19/20 as part of the independent evaluation process to explore what projects reported in terms of the progress made in addressing the identified disparities. Reports were provided by the Department of Disability Services. These reports were uploaded to Caspio™, an online cloud database platform, for ease of review and rating. The results were then added to SPSS © and frequency distributions were conducted. Sections 1a., 1b., 1c., and 2d, described above were used for the analysis. The NCCC Disability Disparities Framework was used to rate the project reports and to answer the following question:

To what extent do the projects report their progress or outcomes in reducing disparities or advancing equity in availability, accessibility, acceptability, quality and utilization?

The NCCC Disparities Framework defines each of these factors as follows:

- **Availability** of supports and services including the array, type, and intensity.
- **Accessibility** of supports and services such as geographic distribution, hours of delivery, technology, language access, accommodations, and universal design.
- **Acceptability**, which principally involves system capacity to plan, deliver, and evaluate culturally and linguistically competent supports and services to diverse populations across the life course.
- **Quality** of supports and services across diverse populations and communities. Quality in the

context of this framework is defined as the totality of features and characteristics of supports and services that enable systems and organizations to be responsive to and satisfy the interests and needs of a given population.

- **Utilization** rates across culturally and linguistically diverse populations including the types of supports and services.

In addition to these 6 factors, the success stories were reviewed to determine the extent to which they provided an example from the project which included results that were **transferable** for IDD disparities reduction and/or advancing equity across racial, ethnic, and linguistic groups. The results of the review follow this section and are presented for each organization type (i.e., Regional Center or Community-Based Organization).

Results

There were 101 projects from FY 18/19 and FY 19/20 that were reviewed. However, of those projects, there were 16 reports that were not submitted (i.e., 13 Regional Center reports and 3 Community-Based Organization reports). There were 88 reports

reviewed and rated (i.e., 35 reports for Regional Centers and 53 reports for CBOs) The results of the review are presented below in tables 1 and 2.

Results from the analysis of the Regional Center final reports revealed that, for all of the factors of the NCCC Disparities Framework, over 50% of the Regional Centers did not include documentation of progress or outcomes. The largest rating percentage was, 69%, which indicated that a large number of the reports did not document progress in addressing *quality* of supports and services. This was followed by lack of documentation of progress or outcomes for *utilization* at 66%. Almost half of the reports, 47% did report progress or outcomes on *availability* of supports and services. For the CBO ratings, the results were similar in that the largest rating percentage was 66%, which indicated that a large number of the reports did not document progress in addressing *quality* of supports and services. The lack of reporting of progress in *utilization* was almost even. For both Regional Centers and CBOs, transferability of the success stories was rated affirmatively for just over 40% of the reports.

Table 1: Regional Center Report Review and Ratings

Regional Centers (n=32)	Yes	No
Availability of supports and services including the array, type, and intensity	47%	53%
Accessibility of supports and services such as geographic distribution, hours of delivery, technology, language access, accommodations, and universal design	44%	56%
Acceptability which principally involves system capacity to plan, deliver, and evaluate culturally and linguistically competent supports and services to diverse populations across the life course	41%	59%
Quality of supports and services across diverse populations and communities	31%	69%
Utilization rates across culturally and linguistically diverse populations including the types of supports and services	34%	66%
Transferability of the story or results for IDD disparities reduction and/or advancing equity across racial, ethnic, and linguistic groups.	41%	59%

Table 2: Community-Based Organizations Report Review and Ratings

Community Based Organizations (n=53)	Yes%	No%
Availability of supports and services including the array, type, and intensity	42%	59%
Accessibility of supports and services such as geographic distribution, hours of delivery, technology, language access, accommodations, and universal design	47%	53%
Acceptability which principally involves system capacity to plan, deliver, and evaluate culturally and linguistically competent supports and services to diverse populations across the life course	38%	62%
Quality of supports and services across diverse populations and communities	34%	66%
Utilization rates across culturally and linguistically diverse populations including the types of supports and services	50%	49%
Transferability of the story or results for IDD disparities reduction and/or advancing equity across racial, ethnic, and linguistic groups.	45%	55%

The following issues were noted in the review of reports:

- The reports often did not clearly align the description of activities or results to the disparity that was being addressed or the equity effort that was being advanced. In many instances the objective did not include mention of the population or gap in services that was being addressed, so it was difficult to ascertain the impact.
- The majority of the success stories did not include enough information to determine if the results were **transferable** for disparities reduction and/or advancing equity for individuals with developmental and intellectual disabilities across racial, ethnic, and linguistic groups.
- In reporting outcomes of the project, exact numbers were rarely presented. In many instances, results were reported as an estimate, such as “about 60 families”.
- Most of the items rated as availability had to do with increasing awareness or the availability of resource centers and not increasing actual service array, type, and intensity.
- COVID was mentioned in reports as negatively impacting project implementation and progress.

To improve the reporting process, it is recommended that funded projects receive a report template which includes specific metrics that can be analyzed across projects, such as number of participants representing the population of focus and the changes achieved based on the activities of the project. Training on project reporting requirements, including the structures that need to be in place for evaluation of the project activities, such as logic model development and how to report implementation, outcome and impact data, will enhance the reporting process and provide important information for replication.



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