



**NATIONAL CORE INDICATORS CHILD FAMILY
SURVEY 3: FISCAL YEAR 2018-2019**

Results and Analysis

December 15, 2021

Introduction

The National Core Indicators (NCI) program began in the mid-1990s as a collaboration between the National Association of Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI) to create an accurate, valid, reliable, and standardized measure of the satisfaction of the individuals served and their families with the performance of the developmental disabilities services system. Since then, most states, districts, and territories participate in the use of the NCI as part of their quality assessment and management programs. Modified versions of the NCI are in use by other countries in Europe and Southeast Asia as well.

The NCI is a series of surveys for individuals served, their family, guardians, and caregivers. In 2010, the California Legislature directed the Department of Developmental Services (DDS) to collect satisfaction measures along with individual outcome data¹. That data is used to review and benchmark performance by each regional center individually as well as statewide. Responses to a survey² are collected by the State Council on Developmental Disabilities (SCDD) regional offices each fiscal year and sent to HSRI for analysis and comparison to results by other regional centers and with other states.

On September 10, 2021, DDS published the results of the Child Family Survey conducted during Fiscal Year 2018-2019. Those results for San Andreas Regional Center (SARC) are presented and discussed in this report. There are two important caveats: First, the answers reflected here only encompass families who have a child service recipient who *lives with them* and receives at least one service other than case management. Second, this survey was conducted *before* the COVID-19 pandemic; given both its lag in age and the upheaval the pandemic has caused for families, providers, and regional centers, the information given here is a good look at San Andreas's community at that moment in time but will not provide a qualitatively or quantitatively accurate portrayal of our current moment. Another Child Family Survey is being conducted for this fiscal year (2021-2022) and will offer an interesting point of comparison when that report is finally released.

An effort has been made to include community feedback throughout the report: Following public presentation of HSRI's findings on November 15, 2021, an open period for public comment was made available until November 30, 2021. This report, our initial presentation, and the reports and data from HSRI are all available at our website. We remain committed to the community we serve and look forward to the discussions and changes the information that follows may spur.

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NCI Coordinator

¹ Welfare and Institutions Code (WIC) §4571

² Adult In-Person Survey, Adult Family Survey, Family Guardian Survey, and Child Family Survey. Additionally, outcomes for Developmental Center leavers are tracked using the Mover Longitudinal Study, a version of the Adult Consumer and Family Guardian Surveys modified by the University of California, Davis for DDS.

Demographics³ of the Child Receiving Services

768 SARC families responded to the survey; 23% of SARC respondents reported having more than one child in the home with an intellectual/developmental disability, compared to 25% statewide and 26% nationally. The average age of the child served was just under 12 years old; 70% of the children were male for SARC, in keeping with the state and national averages (72% and 69% respectively).

The survey queried families regarding their child's disabilities; responses were not mutually exclusive. In terms of regional center-eligible conditions (intellectual disability, autism spectrum disorder, cerebral palsy, and epilepsy; conditions similar to or requiring treatment similar to intellectual disability were not tracked explicitly), 36% of SARC respondents reported intellectual disability, 69% autism spectrum disorder, 10% cerebral palsy, and 13% epilepsy. This was in keeping with the state's overall numbers; however, both SARC and California served a higher proportion of individuals reporting autism spectrum disorder than the national average, and fewer (nearly 5% for SARC) than the national average for epilepsy. Other conditions reported by SARC families included mental illness (13%; higher than the state average of 10%), vision and/or hearing (7%), and one or more other health conditions (42%). Overall, these numbers are in keeping with state and national numbers, with a couple of interesting exceptions: SARC and California report far lower incidence of high cholesterol among children served, and SARC's reporting of sleep apnea (32%) was well-above the state and national reporting (24% each).

The three ethnicities (as defined and tracked by NCI) that made up most respondents for SARC were Asian (39%), Hispanic/Latino (37%), and White (34%); Native American, Black/African-American, Pacific Islander, and Other groups represented 3% of respondents or fewer, respectively. In terms of communication, 63% of respondents reported their child could speak (compared to 71% statewide and 69% nationally). The vast majority of SARC respondent families (89%) preferred to communicate using English.

The survey also inquired around areas of need. 71% of SARC respondents reported "some" or "extensive" need for supports regarding self-injurious, disruptive, or destructive behaviors; 74% of California and 68% national respondents answered similarly. 93% of SARC respondents reported "some" or

³ The statewide numbers for California were gathered by valid survey responses from 10,630 Child Families across all 21 regional centers. National numbers are calculated by HSRI through the weighted use of 14,816 valid surveys collected from 12 of the participating states (including California). Demographics were collected regarding both the child served and the respondent answering the survey as well as regarding the nature of the services received. Some questions are "California specific" at the request of DDS and will not have national comparison data. Of further note, the nature of California's regional center system is unique and the survey results may, due to our system's structure, encompass served individuals up to 22 years old.

“extensive” need for help with personal care activities, in keeping with California and national numbers (92% for both).

Demographics of Respondent

Respondents were not tracked by geographic location. 55% of SARC respondents spoke English at home, followed by 18% speaking a form of Chinese and 16% speaking Spanish. While this represents a lower number of Spanish-primary respondents compared to California as a whole, the number of Chinese-speaking respondents for SARC was triple the number of the state’s and nearly 20 times the relative amount nationally. Nearly all (98%) of respondents were the parent of the child, with 87% under the age of 55 and over three-quarters aged 35 or older. A small but sizable number of respondents (12%) were single parents, lower than found statewide and nationally. Almost all SARC families, 91%, reported living in urban or suburban areas, consistent with California and higher than the national average. For SARC, as found across the state and the nation, just over one-third (35%) of respondent families were single-child. 50% of SARC families reported an income at or higher than \$50,000 annually, higher than both California and the nation (38% and 42%).

A majority (58%) of SARC families made use of programs such as In-Home Support Services, allowing the parent or other family members to provide paid support to the child. A plurality of SARC families (46%) paid over \$1,000 out-of-pocket for medical or therapeutic expenses compared to 34% in California. Nearly one out of ten – 9% -- of SARC families reported paying more than \$10,000 annually, higher than the statewide average. Services covered by SARC families out-of-pocket included respite (17%), behavior therapy (19%), speech therapy (26%), social recreation (46%), afterschool care (35%), medical/dental care (54%), and transportation (24%). SARC families reported more funding out-of-pocket across all areas compared to California families, other than medical/dental care, which was consistent with the statewide reporting.

Responses in green text are equal to or better than state averages, whereas red are worse. Due to the nature of how questions are worded, there are occasions where a question’s context is slightly counter-intuitive in terms of whether a lower or higher average is desired; the red/green distinction attempts to reduce this confusion. The Child Family Survey uses a framework of “always,” “usually,” “sometimes,” or “seldom/never” for responses, except when a more detailed answer is requested. For the purposes of this analysis, “always” and “usually” will be termed positive responses, as opposed to “sometimes” or “seldom/never,” which shall be deemed negative.

Services and Supports Received

These questions were specifically intended to discuss supports received from or funded by regional centers.

None of the SARC families surveyed currently participated in the Early Start program, though two-thirds had, slightly under the state average. One-quarter received financial support, nearly half received support in the home (43%) and/or out-of-home respite (45%), with just under one out of five (17%) reporting the use of self-determination or fiscal management services. Approximately one-quarter (26%) of SARC respondents stated their child received Social Security payments. In close keeping with the state average, 64% of SARC families reported receiving supports or services from other agencies. 55% responded positively when asked if they received enough information to take part in planning services. 64% responded positively when asked if the information received was easy to understand. 90% reported positively that their service coordinator respected family choices and opinions. 56% reported positively that they received enough information about other public services.

The survey asks families about different areas of planning that they may need assistance with from their service coordinator, including employment, financial assistance, housing, legal assistance, medical care, social relationships, transition from school, and recreation; a majority of SARC respondents responded that they needed assistance in all areas, and in all areas SARC's respondents reported needs at rates the same or higher than the rest of California and the nation. Needs around housing, legal, and medical assistance were notably above the state and national averages, with social recreation being the most-sought area of assistance.

79% of respondents reported having an Individual Program Plan and 81% of these reported that their child's IPP included all their service and support needs. While 88% reported that they received all services listed in the IPP, only 37% responded positively when asked if they had received crisis or emergency services upon request in the past year. SARC families overwhelmingly (82%) reported helping to make their child's IPP; however, 86% reported that the child had no role in planning the IPP – sadly only slightly higher than the four out of five respondents statewide and nationally who replied in the same way. Only 32% of SARC respondents stated they had discussed how to handle emergencies at their last meeting (significantly below both state and national levels). While SARC was below average in the number of respondents who stated their child had a transition plan (64%), SARC was above both state and national averages for those who stated they had helped make the transition plan (89%). Fewer than two-thirds (63%) of SARC families felt prepared to handle the needs of their child in a medical or natural emergency.

Access to and Delivery of Services

These questions are meant to determine if children and families are receiving the services and supports they need.

When asked if they can contact their child's support workers when they want to, **79%** of SARC families responded positively and **81%** reported being able to contact their service coordinator when wanted. Fully **89%** reported that their child's workers come and leave as planned; however, only **69%** reported that their child's services and supports could change in keeping with the family's needs. **92%** of families reported that they could communicate effectively with their children's support workers. When asked if services were delivered in a way that respects the family's culture, **96%** responded positively. Fewer than half (**46%**) reported positively that support workers could communicate well with children who did not communicate verbally, and only **80%** felt that support workers had the correct information and skills to meet their child's needs. Over a quarter (**27%**) of SARC families felt their child did not have the special equipment or accommodations they need. When asked if their child could see health care professionals as needed, **92%** responded positively with **89%** of those reporting their primary care physician understood their child's needs relative to their disability. Only **84%** of SARC families reported that their child could access dental care when needed, with **84%** of those responding that their dentist understood their child's needs. For those families whose children required mental health services, **81%**⁴ reported that their provider understood their child's needs. When asked about respite services, **76%** reported positively regarding access and **83%** reported satisfaction with the quality of services. Fewer than two-thirds (**63%**) of SARC families reported receiving the overall supports they required: Areas queried for added supports include respite (**40%**), regularly scheduled support (**35%**), homemaker services (**21%**), home and vehicle modifications (**17%**), counseling (**36%**)⁵, family to family networks (**26%**), or others (**39%**).

Choice, Decision Making, and Control

Families were asked if they determine which services and supports they receive and the individuals or agencies who provide them.

Only **75%** of SARC families felt they could choose or change their child's service providers. Even fewer, **69%**, felt they could change their child's assigned staff. **71%** of SARC families felt their providers worked together, better than the state average. While few families (**12%**) felt they chose their service coordinator, **64%** knew they could change their service coordinator, and **24%** felt they cannot change service coordinators if they want to.

Involvement in the Community

⁴ The state and national averages are 84%, still unacceptably low.

⁵ California, including SARC, is below the national average in providing counseling to IDD children.

Families were asked if they used integrated community services and participated in everyday community settings and activities.

Over three-quarters (78%) of SARC families stated their child participated in community activities and the vast majority (87%) stated their child spent time with children who did not have developmental disabilities⁶. However, when asked if they spent time with children who were not siblings and did not have a developmental disability, the number of positive responses fell (72%). When asked, SARC families reported a variety of barriers to community inclusion including, but not limited to, lack of transportation (10%), cost (22%), lack of support (25%), and stigma (31%). Fewer SARC families (74%) felt that there were non-regional center resources in the community for their children than other families in California or the United States as a whole; however, more SARC families stated that they participated in family-to-family networking (32%) compared to both the state and the nation⁷.

Satisfaction with Services and Supports

This section of the survey is intended to gauge whether children and families are receiving adequate and satisfactory services.

SARC families expressed overall positive satisfaction with their services and supports (71%), below the state average. Notably fewer SARC families knew how to file a complaint or grievance regarding their services (35%) and of those who had (approximately 11% of respondents), significantly fewer (44%) expressed satisfaction with the handling and resolution. The survey did *not* distinguish between complaints made to SARC directly or to the service provider. Fewer SARC families (59%) knew how to make a report of abuse or neglect of their child. The number of reports of abuse or neglect, however, were in keeping with state and national averages.

The vast majority (90%) of SARC families expressed that regional center services had made a positive difference in their lives. SARC families were more likely (78%) to state that regional center services had reduced out-of-pocket expenses for the family. SARC families were slightly more likely (87%) to state that regional center services had improved their ability to care for their child; however, those who stated their services had been reduced or terminated in the past year (17%) were much more likely to say that the reduction or termination affected the family negatively (80%) than other regional center families⁸. One in five SARC families (19%), fewer than the state average, stated that their services had been increased; that said, SARC families were just as likely (90%) to state

⁶ Both SARC and California are in keeping with the national average for children spending time with typically-developing peers.

⁷ SARC exceeded the state and national averages by 9% and by 11%, respectively.

⁸ Whereas the state average is on keeping with the nation's (66%).

that their services were helping their child to live a good life and to keep their child in their home (82%).

Conclusions and Implications

Respondents' use of respite services exceeded state averages; respite has for years been the most consistently-requested service from SARC's families with children in the home. SARC families had the second-highest rate of receiving financial assistance from their regional center, exceeded only by Golden Gate Regional Center (serving San Francisco and San Mateo counties); though to-date no study has been done to specifically draw a causal relationship, research has shown that healthcare costs in the Bay Area exceeded the rest of California by at least 30%⁹. It is reasonable to hypothesize that more SARC and GGRC families required assistance with co-pays and co-insurances than other regional centers. Similarly, SARC families were more-likely to have accessed federal and state assistance and benefits than the state average. There is no reason to assume this figure has changed in recent years.

Too few SARC families felt they received sufficient, understandable information to make informed decisions regarding their child's individual program plan, services, and supports, even though a higher proportion than the state average indicated they had participated in formulating the IPP. While nine out of 10 SARC families felt respected by their service coordinators, this number still fell below the state average; similarly, while SARC exceeded the state average in informing its families regarding other public services, that number just exceeded one out of every two. Still, a higher-than-average amount of SARC families reported being satisfied with their children's IPPs and in receiving the services articulated in the IPP. Discussion of crisis and emergency planning was concerningly below average, with under two-thirds of SARC families stating they felt prepared to respond to their child's needs in an emergency or crisis.

SARC family responses pertinent to our service providers were most often below state averages. Fewer SARC families felt they could contact or communicate with their child's support workers than average. Only four out of five families felt their child's support staff had sufficient skills and training to work with their child. The ability of service workers to communicate, especially with recipients who do not speak, is a particular area of concern. Access to knowledgeable dental care and to adaptive equipment both fell below state averages. While less than two-thirds of SARC families said they received the overall supports they required, four out of every five said their IPPs included all supports they needed and nine out of 10 said they received the services and supports listed in the IPP.

⁹ *Consolidation in California's Healthcare Market 2010-2016: Impact on Prices and ACA Premiums*, Nicholas C. Petris Center on Health Care Markets and Consumer Welfare, School of Public Health, University of California, Berkeley, March 26, 2018.

Three out of four SARC families felt they could choose or change their providers. The survey is not clear whether this result was driven primarily by lack of awareness of their ability to choose, a sense of choice not being respected (which would be hard to reconcile with the earlier finding that SARC families felt their choices respected), or a lack of providers. While the law clearly allows for families to ask for a change in service coordinators, one out of every four families felt they could not request to change theirs. Given that trusting relationships are the single most key component to a regional center's relationship with the people it serves, these numbers, which are worse than the state averages, require further inquiry.

While fully one-third of all regional centers had families that reported a higher degree of community inclusion than SARC's, it is important to note that three of those seven regional centers all cover the same county – Los Angeles. SARC families reported more use of family-to-family networks and more reliance upon siblings for inclusion with typically-developing peers. SARC families reported more stigma and fewer community opportunities from the general community when compared to other regional centers' communities. These statistics were not broken down by SCDD, DDS, or HSRI by zip code or county, making them unfortunately of little use in identifying local communities to dedicate additional community service development efforts and advocacy to. However, given that SARC scored lowest in the state on the availability of community resources and opportunities that are **not** provided by the regional center – a full six points below the state average, which is already below the national average – it is reasonable to conclude that all four SARC counties have pronounced room for improvement.

While SARC families were overall satisfied with their services and supports, this was a lower proportion than the state average. That said, SARC families were more likely to have found their regional center services and supports a positive influence on their lives, including reducing out-of-pocket expenses. Given the lack of non-regional center supports available, the positive effect of SARC's system of services and supports, and that the reduction of said supports were more likely to cause a negative effect on the families we served, an overall picture emerges that SARC plays an oversized, vital role in its families' well-being and their ability to keep their loved ones safe, healthy, and included in their communities.

Commentary

While the public commentary period has closed, San Andreas Regional Center encourages members of the public, community stakeholders, individuals served, and their families and advocates to reach out to discuss any questions or concerns they may have. The NCI indices provide good starting points for discussions around equity in purchase of service usage and distribution, regional center practices, community inclusion, and needs and services. However,

without discussion by and from the communities we serve, we are less able to identify and advocate for the supports they need. Participation, both through regional center solicitation and community advocacy organizations, is necessary, but cannot replace the voices of people with intellectual and developmental disabilities themselves.

Community Feedback

Public commentary was solicited by SARC, beginning at its public presentation on November 15, 2021, through November 30th. The only comment received from the public was from David Grady, Regional Manager for the State Council on Developmental Disabilities, who stated that the NCI does not provide enough of a qualitative picture of the nature and quality of supports received by California's children with developmental disabilities and their families.

Contact

Inquiries, commentary, and critiques are encouraged. Please contact SARC's NCI Coordinator to begin your discussion. Interested parties may also contact the SCDD Quality Assessment Project Staff assigned to SARC, and/or DDS.

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Resources

- ❖ San Andreas Regional Center www.sanandreasregional.org
- ❖ California Department of Developmental Services www.dds.ca.gov
 - National Core Indicators Dashboard www.dds.ca.gov/rc/nci
- ❖ National Core Indicators www.nationalcoreindicators.org
- ❖ Human Services Research Institute www.hsri.org
- ❖ National Association of State Directors of Developmental Disabilities Services www.nasddds.org