

SELF-ADVOCATE & FAMILY SURVEY REPORT

March 2022



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SECTION 1: SURVEY SUMMARY

1:1 Background

This survey is a response to feedback from self-advocates, families, community-based organizations, service providers and others during the COVID-19 pandemic. Informal reports from stakeholders and community members indicated that regional center services could be improved in terms of connections with families, family preferences for the way services are provided in the pandemic, and other key aspects of service delivery. These reports inspired DDS's initiative to create a statewide survey that could gather input from individuals in diverse communities. DDS sought input about the content of the survey from many stakeholder groups, including community-based organizations, the Association of Regional Center Agencies (ARCA), the Developmental Services Task Force, the DDS Disparity Workgroup and service providers.

1:2 Objective

The DDS Self-Advocate & Family Survey was designed to help the Department understand how COVID-19 has impacted our communities and changed families' experiences of services. Information from the survey will inform DDS, regional centers and service providers about new ways to safely support families and help identify what's working, what's not working, and what is important to self-advocates and families.

1:3 Main Findings

- Among the 9,064 responses received, nearly two-thirds (64%) of respondents found the support they received during the pandemic to be helpful or very helpful. The sources of support included nonprofit organizations, family or friends, regional centers and service providers.
- Three-quarters (76%) of respondents said the amount of regional center contact they received met their needs. The most important regional center supports were providing information and resources as well as new or additional services.

- One-third (33%) of families would have liked more service coordinator contact or additional services to meet emergency needs.
- Nearly two-fifths (38%) of families received services from a service provider by phone or the internet, and one quarter (25%) received them at home in a safe manner.
- Close to nine out of ten (85%) families were satisfied or very satisfied with their service provider.
- Three out of five (60%) respondents said the best ways to provide them with information are through an email from DDS or contact from a regional center service provider, and nine out of ten (90%) said the internet was important to them during the pandemic.

1:4 Conclusion

The survey results provide a useful measure of the needs and levels of support received by the communities served by DDS and regional centers. The results show that most respondents received the supports they needed and were satisfied with the services provided by regional centers and service providers. However, in some cases the amount of support and levels of satisfaction varied by ethnicity and regional center. The detailed information in the survey results can be a guide to improving equity in service provision and availability.

Because the survey was open to anyone who chose to respond, the responses may not represent all self-advocates or all families. Full responses to the survey are available in an interactive dashboard on the DDS website. ([Link](#))

SECTION 2: WHO TOOK THE SURVEY?

2:1 Who Took the Survey

DDS received 9,064 responses to the survey. Self-advocates submitted 1,587 responses (18% of all surveys); family members submitted 4,392 responses (48%); and legal guardians and conservators submitted 2,663 (29%). Others, including provider staff and community members, submitted 346 responses (4%), and 76 respondents (1%) did not answer this question. (Figure 1)

HOW RESPONSES WERE ANALYZED

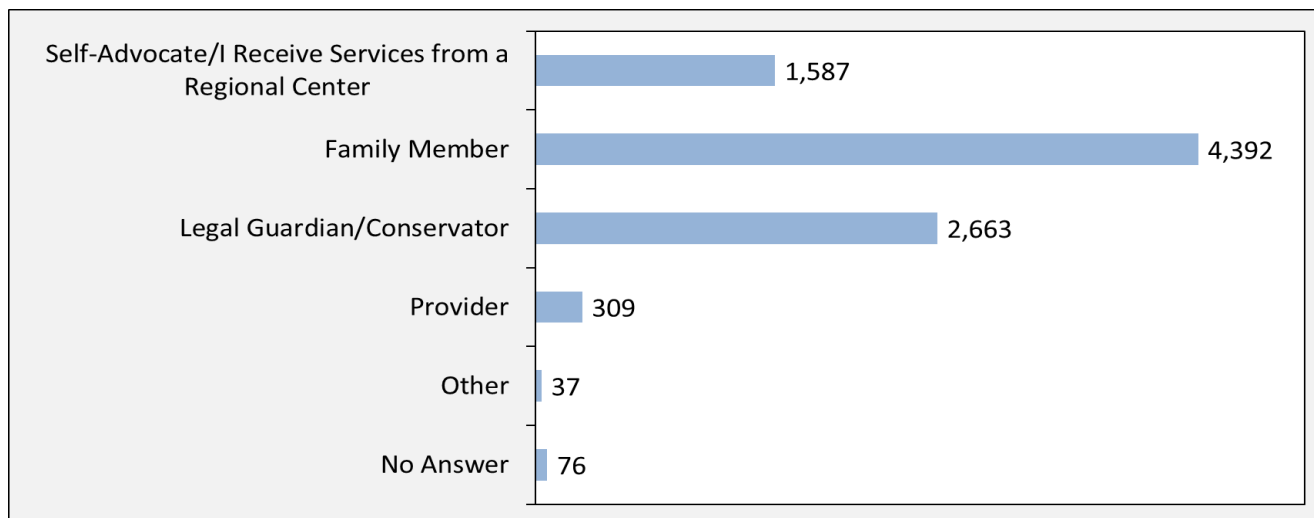
Not all 9,064 respondents answered every question.

Some questions allowed a respondent to choose more than one answer.

Survey respondents who said a question wasn't relevant for them or they didn't know how to answer are excluded from the summary for that question.



Figure 1: How survey respondents are connected to the regional center system



2:2 Survey Implementation

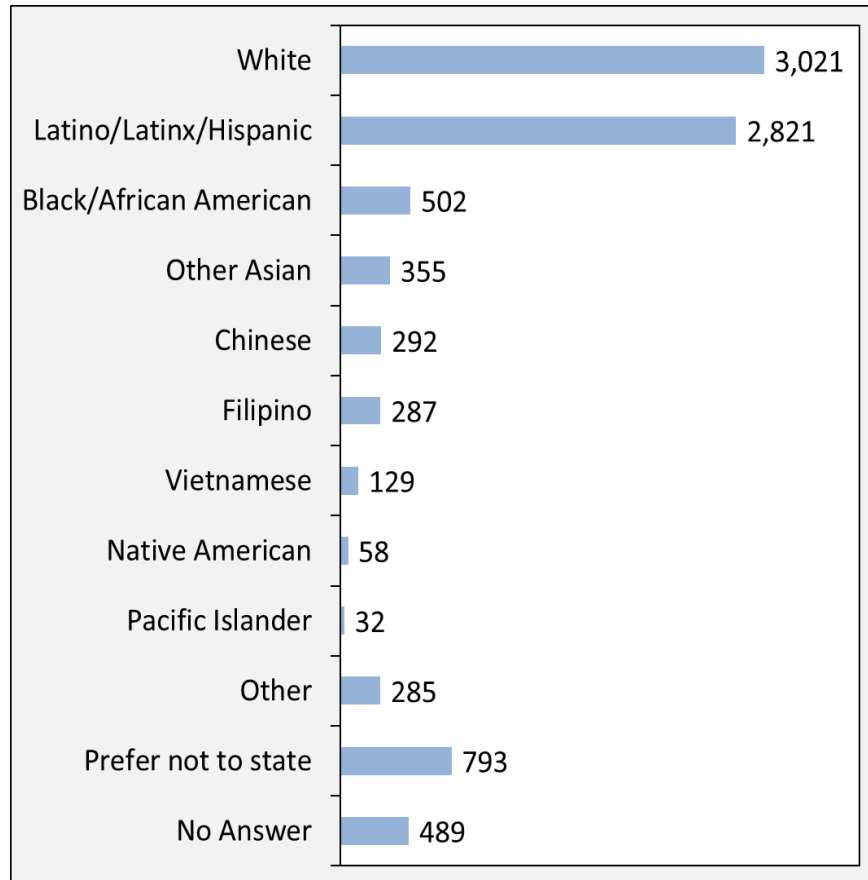
The survey was available on computers and smartphones through the survey platform SurveyMonkey. Links to the survey were emailed to DDS' list of interested parties and posted to its website and Facebook and Twitter pages. Many community organizations forwarded the survey links to their members and included information about the survey in their newsletters and other outreach. The survey was available from November 17 to December 18, 2020 in Arabic, Armenian, Chinese (Simplified and Traditional), English, Korean, Persian, Spanish, Tagalog and Vietnamese.

2:3 Ethnicity

Individuals identifying as White submitted 3,021 surveys (33% of the total), and persons from Latinx/Hispanic communities submitted 2,821 (31%). 502 survey-takers were Black/African American (6%). Smaller numbers of respondents were from Other Asian (355, or 4%), Chinese (292, or 3%), Filipino (287, or 3%), Vietnamese (129, or 1%), Native American (58) or Pacific Islander (32) communities. (This information reflects the individuals completing the survey, not necessarily the consumers they wrote about in the survey.) 1,567 respondents (17%) did not report an ethnicity. (Figure 2)



Figure 2: How diverse ethnic communities participated in the survey



2:4 Language

Most surveys were taken in English (7,734, or 85%), with 1,084 completed in Spanish (12%). 232 respondents chose Chinese, Korean or Vietnamese surveys, and a total of 14 surveys were taken in Arabic, Tagalog, Armenian or Persian (0.2%). (The language someone chose to take the survey in may not be the preferred language of the consumer they reported about.) (Figure 3)

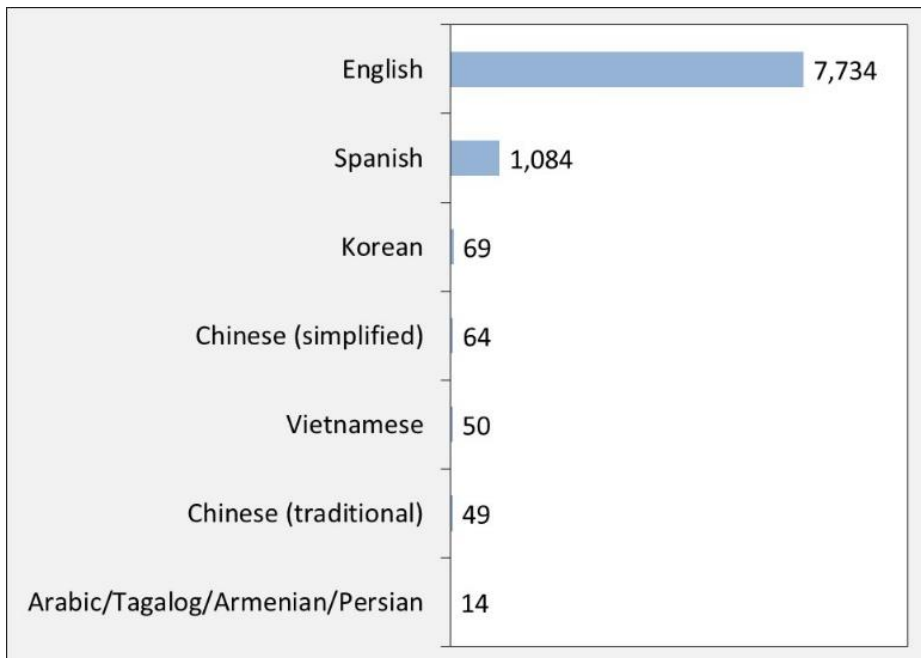


Figure 3: Languages in which the survey was taken

2:5 Age of Self-Advocates and Other Consumers

Survey respondents reported on the experiences of consumers across the lifespan: 981 children from birth through age 2 years; 3,973 individuals age 3 through 21 years; 3,586 adults age 22 through 49 years; 674 adults age 50 through 62 years; and 340 adults age 63 years and older. (Respondents could report the age of more than one individual.) (Figure 4)

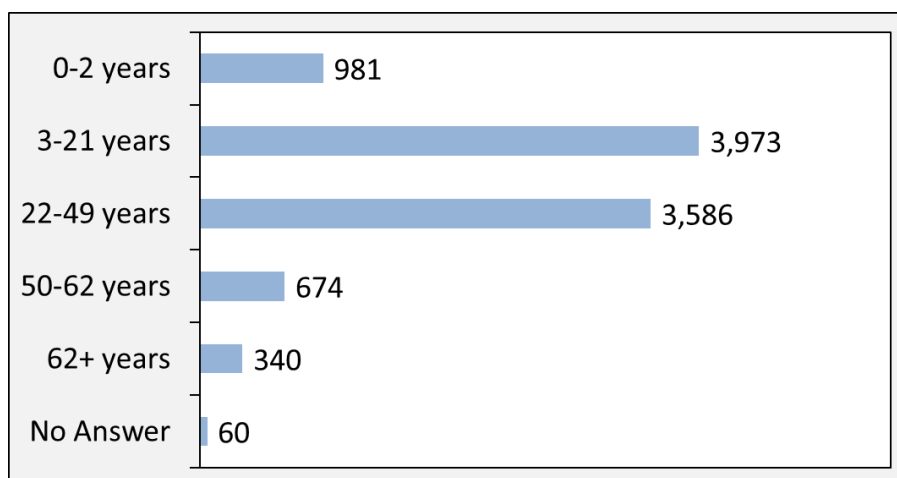
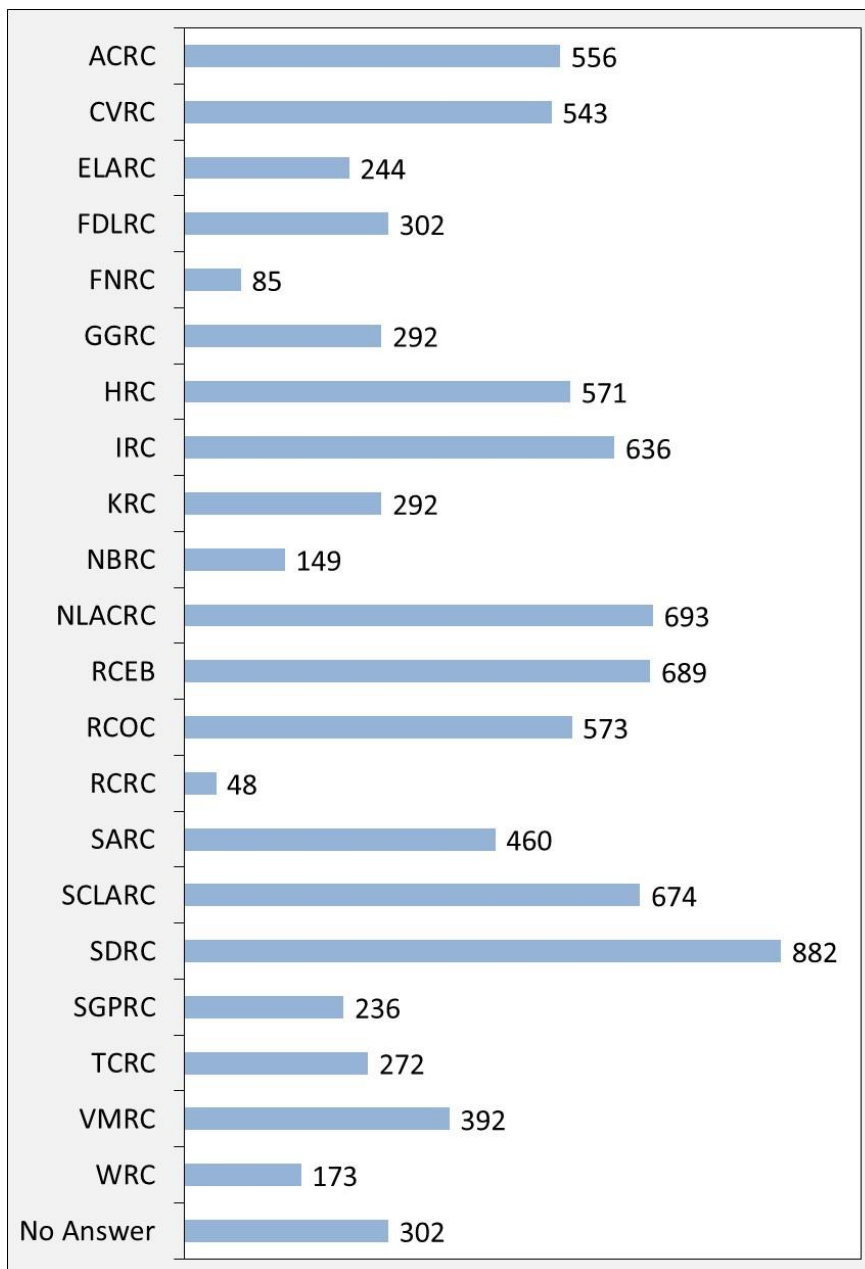


Figure 4: Responses represented consumers across the lifespan

2:6 Regional Centers

Survey respondents represented all regional centers, from the smallest (Redwood Coast Regional Center, with 48 surveys) to the largest (Inland Regional Center; 636 surveys). More surveys were submitted from San Diego Regional Center (882) than any other regional center. (Figure 5)

Figure 5: Surveys were submitted from each regional center area



SECTION 3: WHAT RESPONDENTS TOLD US

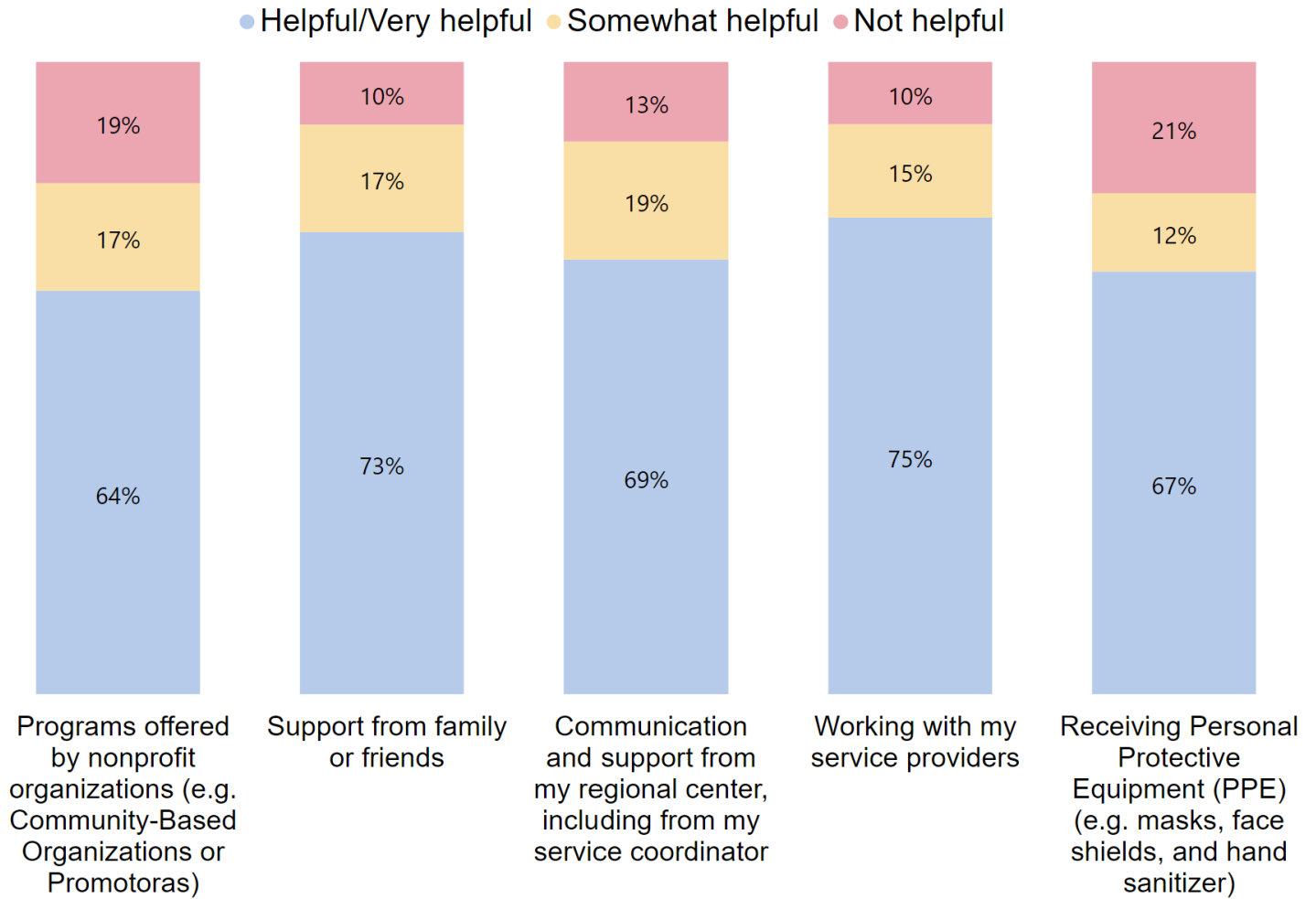
3:1 Sources of Support During the Pandemic

Families found many sources of support in their communities and from regional centers and service providers.

The survey asked if five types of support were helpful during the pandemic. Ninety percent (90%) of respondents noted that support from their service providers and from families or friends had been helpful. Regional centers (87%) and personal protective equipment (79%) were identified as important supports as well. A significant share of respondents (81%) pointed to community-based organizations as helpful. (Figure 6)



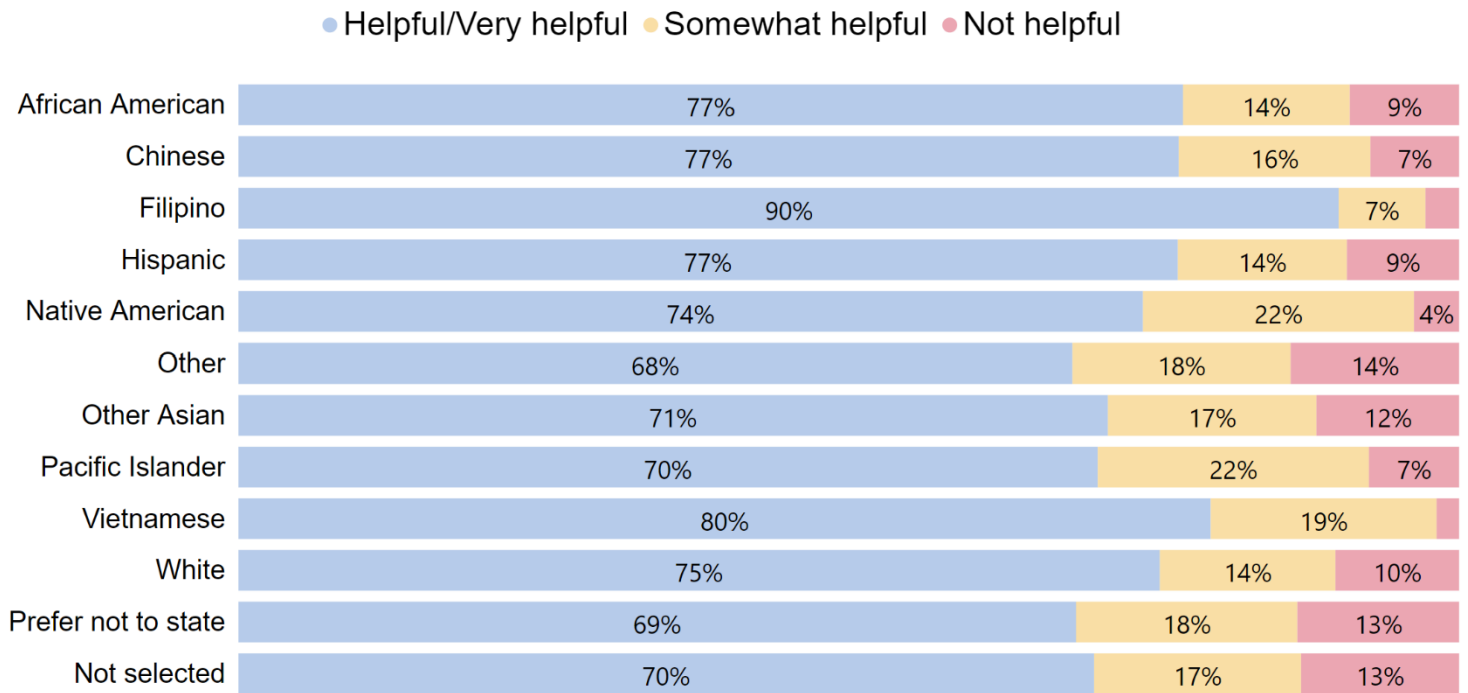
Figure 6: Sources of support



Respondents in all ethnic groups tended to report their service provider as being helpful.

Providers were deemed most helpful by Filipino respondents (97%), followed by Vietnamese (99%). All other groups reported in excess of 85% for the helpfulness of their service provider. (Figure 6a)

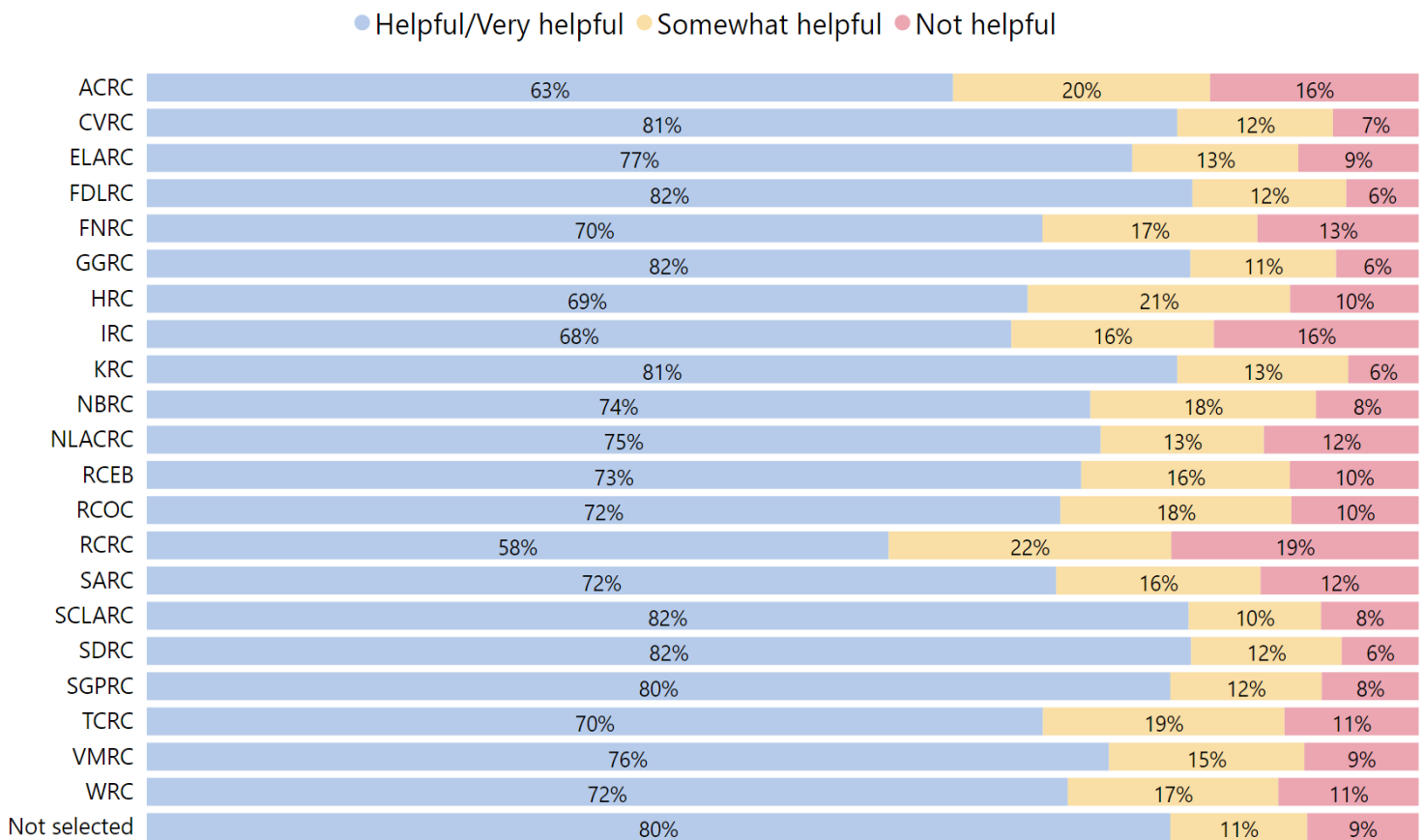
Figure 6a: Working with my service provider, by ethnicity



Respondents in all regional centers tended to report their service provider as being helpful.

More than 80% of respondents in all regional centers reported that their service provider was helpful. In over half the regional centers, this positive outcome was reported by more than 90% of survey respondents. (Figure 6b)

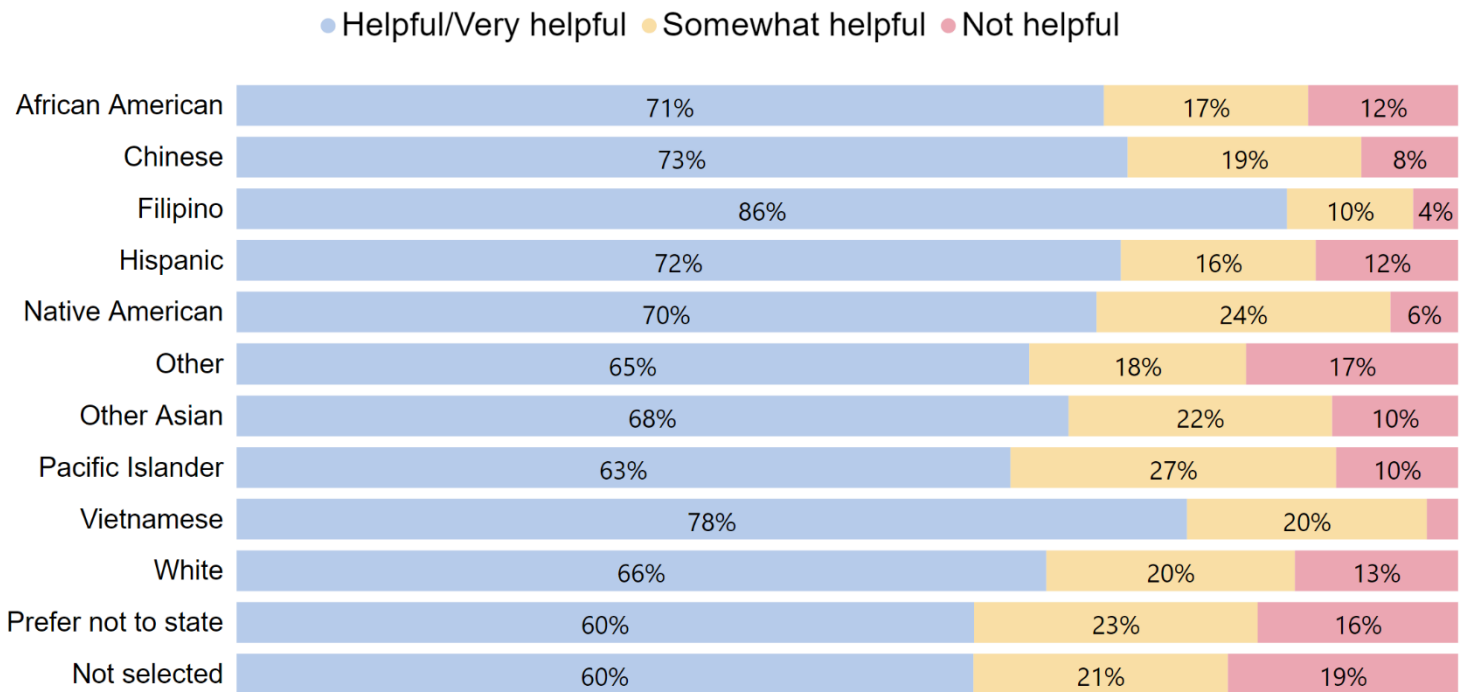
Figure 6b: Working with my service provider, by regional center



Regional center supports were more important in some ethnic communities and some regional centers than others.

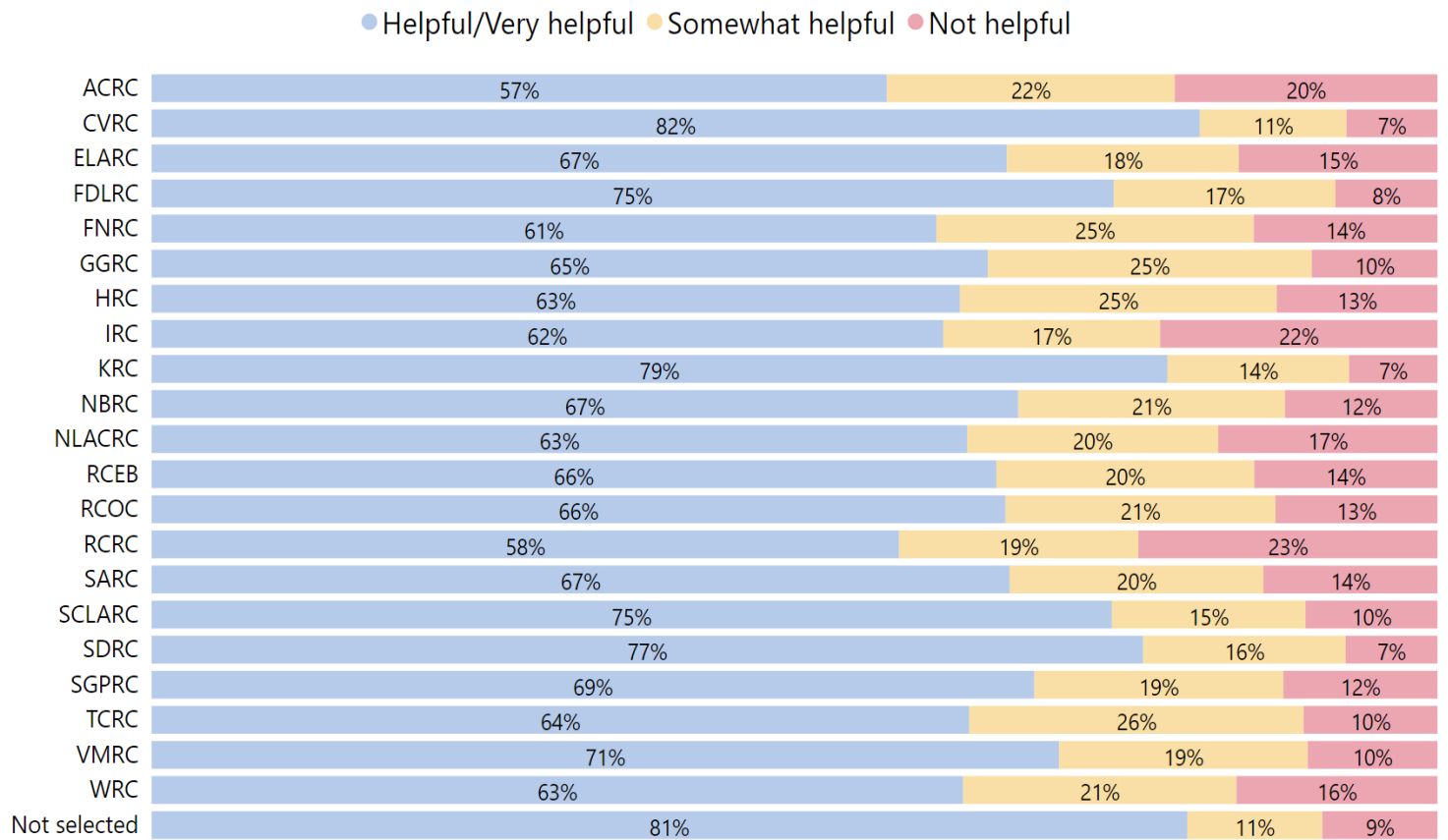
Vietnamese respondents were the most likely to say their regional center was helpful (98%), followed by Filipino respondents (96%). Regional centers were important supports to over 80% of all other groups. Respondents identifying as Other Asian, White and Pacific Islander reported lower levels of helpfulness. (Figure 6c)

Figure 6c: Communication and support from my regional center, including from my service coordinator, by ethnicity



More than 75% of respondents in all regional centers reported that the communication and support from their regional centers was helpful. In most regional centers (16 out of 21 total), 85% of respondents selected this response. (Figure 6d)

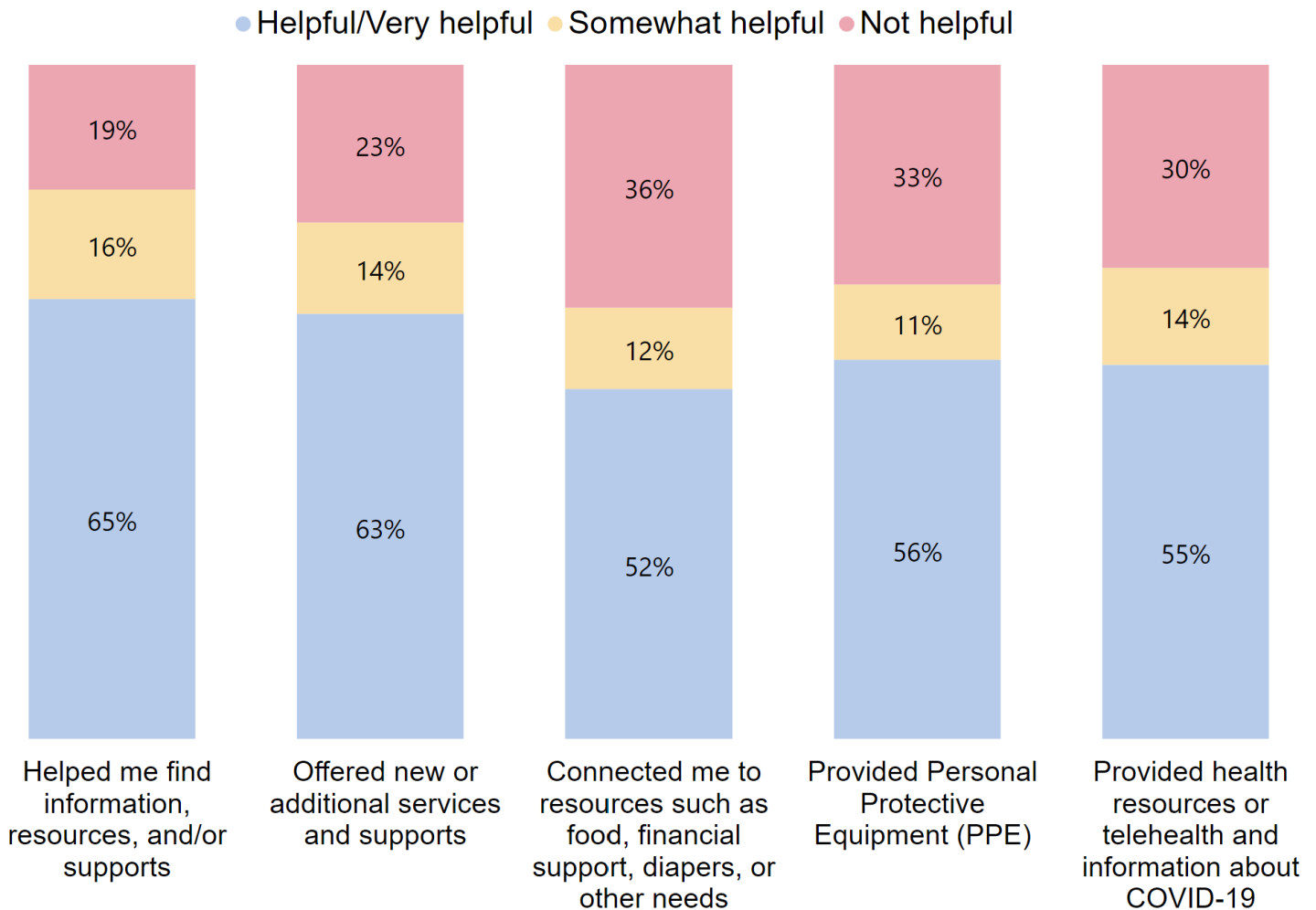
Figure 6d: Communication and support from my regional center, including from my service coordinator, by regional center



The most important regional center supports were providing information and new or additional services.

Respondents were asked if five types of support were helpful during the pandemic. Approximately 8 out of 10 of survey respondents reported that their regional center had served as a helpful source of information and that the newly offered or additional services were helpful. Of those who received assistance with basic needs, PPE or information about COVID-19, over 65% found their regional center to have been helpful. (Figure 7)

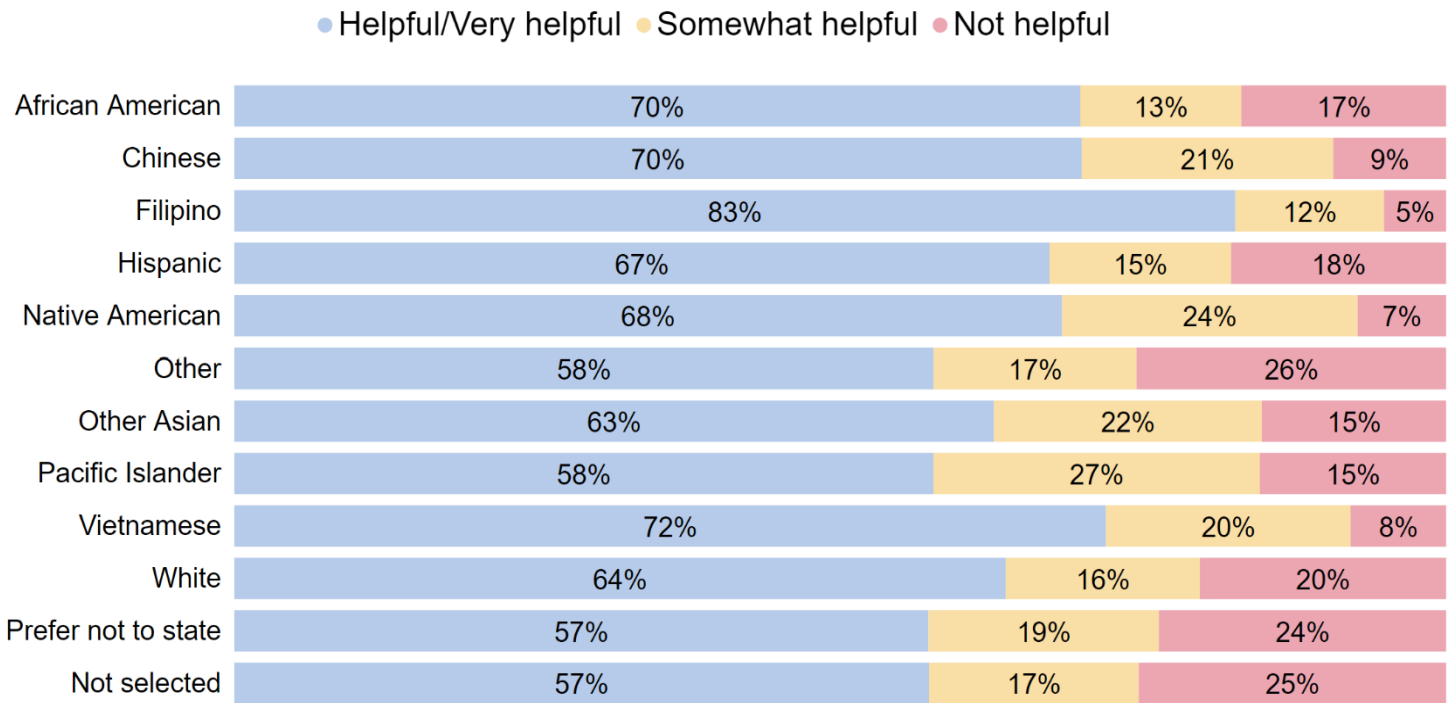
Figure 7: Regional center supports



Information, resources and supports from their regional center were more important in some ethnic communities and some regional centers than others.

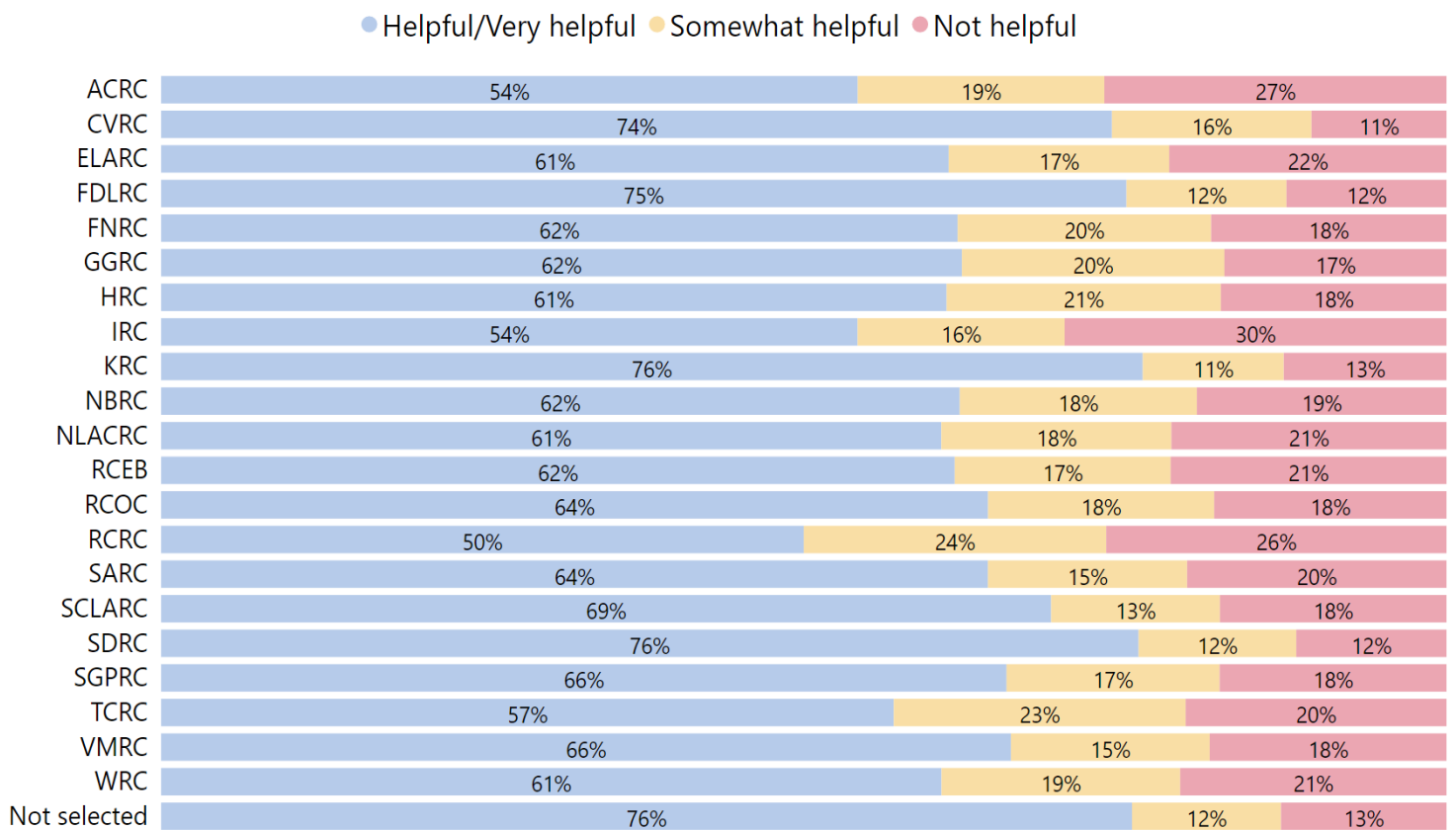
Filipino respondents were most likely to say that this was helpful (95%), followed by Vietnamese (92%), African American (83%), and Chinese (91%) respondents. Approximately 75% of all other respondents reported this regional center support was helpful. (Figure 7a)

Figure 7a: Helped me find information, resources, and/or supports, by ethnicity



More than 69% of respondents in all regional centers reported that information, resources and supports from their regional centers was helpful. In seven regional centers, more than 80% of respondents selected this response. (Figure 7b)

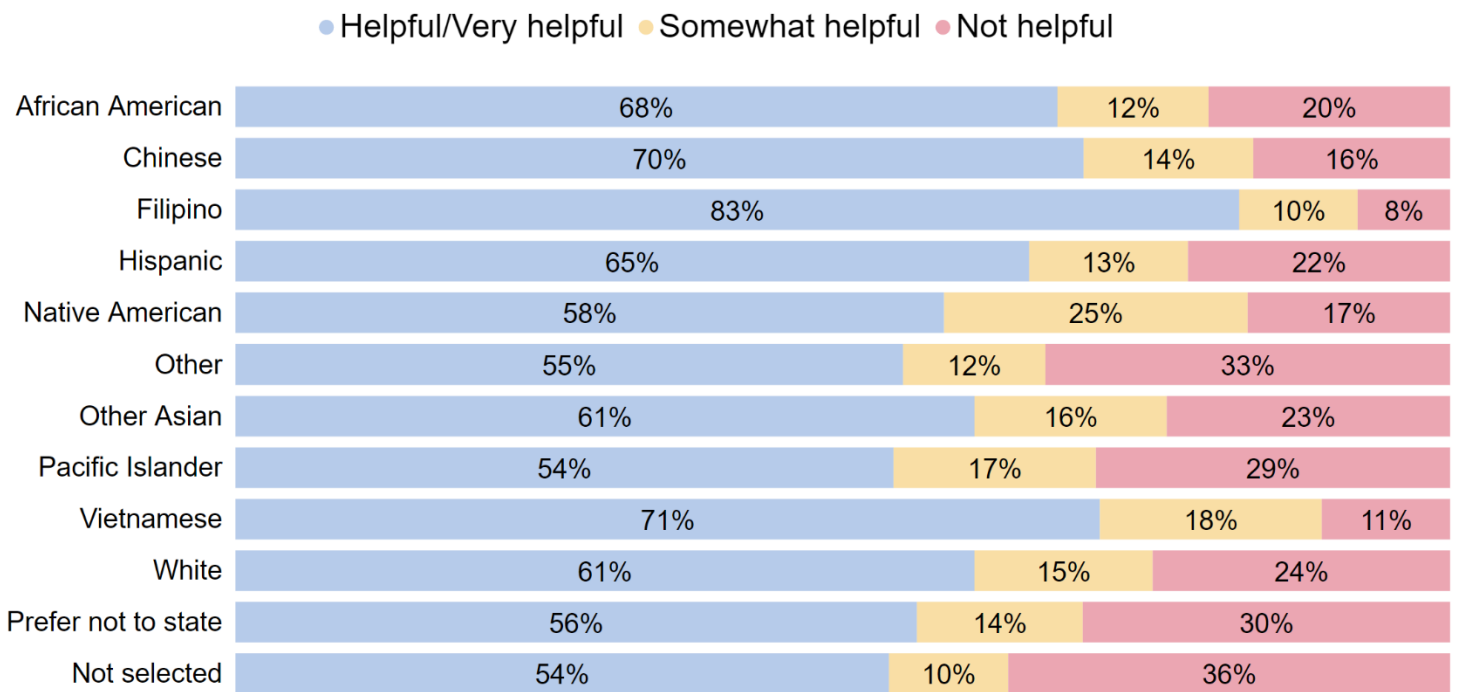
Figure 7b: Helped me find information, resources, and/or supports, by regional center



New or additional services were more important in some ethnic communities and some regional centers than others.

Filipino respondents were most likely to say that new or additional services from their regional center were helpful (92%), followed by Vietnamese (89%), Chinese and African American respondents with over 75%, and White, Other Asian and Other respondents at approximately 70%. (Figure 7c)

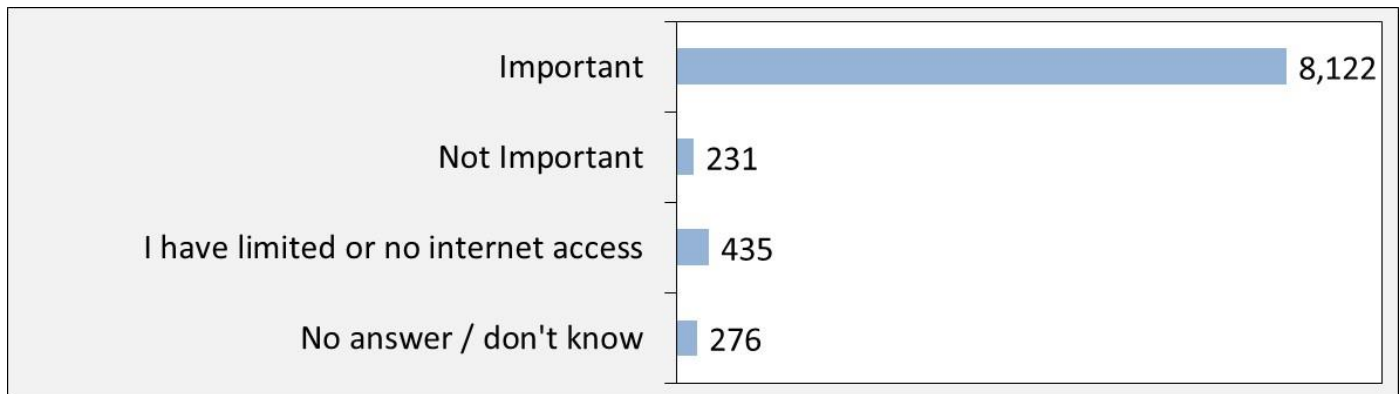
Figure 7c: Offered new or additional services and supports, by ethnicity



The Internet was a key support for respondents to the online survey.

Nine out of ten survey respondents said the internet was important to them during the pandemic. Only 2% said it was not important. 5% had limited internet access or no access. (Figure 8)

Figure 8: Importance of the internet



Nearly two out of five respondents who reported having limited internet access or no access to the internet are Hispanic (39%), and nearly one-third are White (31%). 4% are African American (data not shown in the chart).



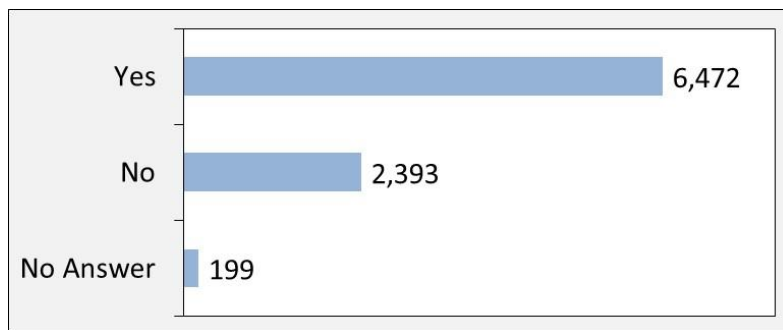
Some individuals who face barriers using the internet may not have been able to take this survey. Families with limited or no internet may have experienced challenges in both service access and opportunities for social connection.

3:2 Satisfaction with Regional Centers

Most families reported getting the support they needed from their regional center

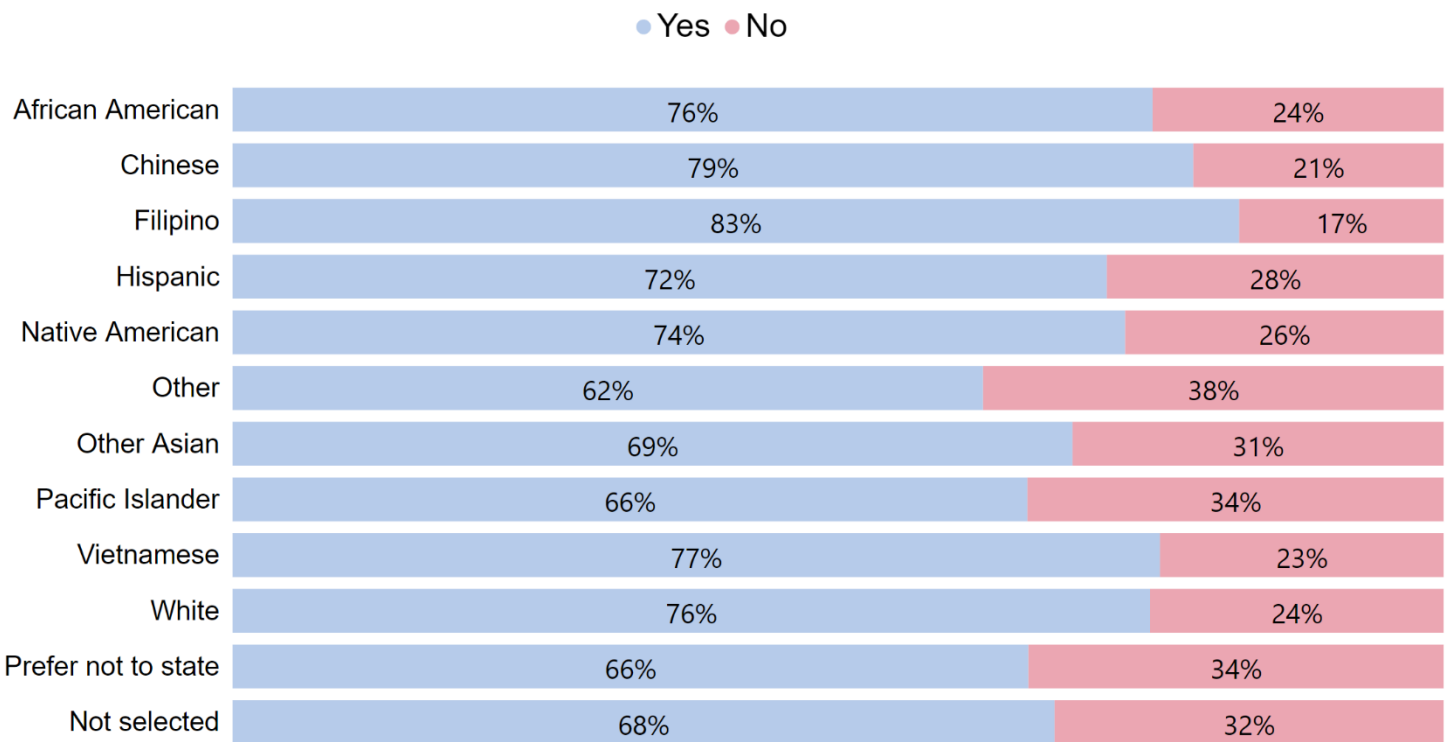
Seven out of 10 survey participants said they got the support they needed during the pandemic from their regional center. Three out of 10 said they did not. (Figure 9)

Figure 9: Getting the regional center support respondents needed



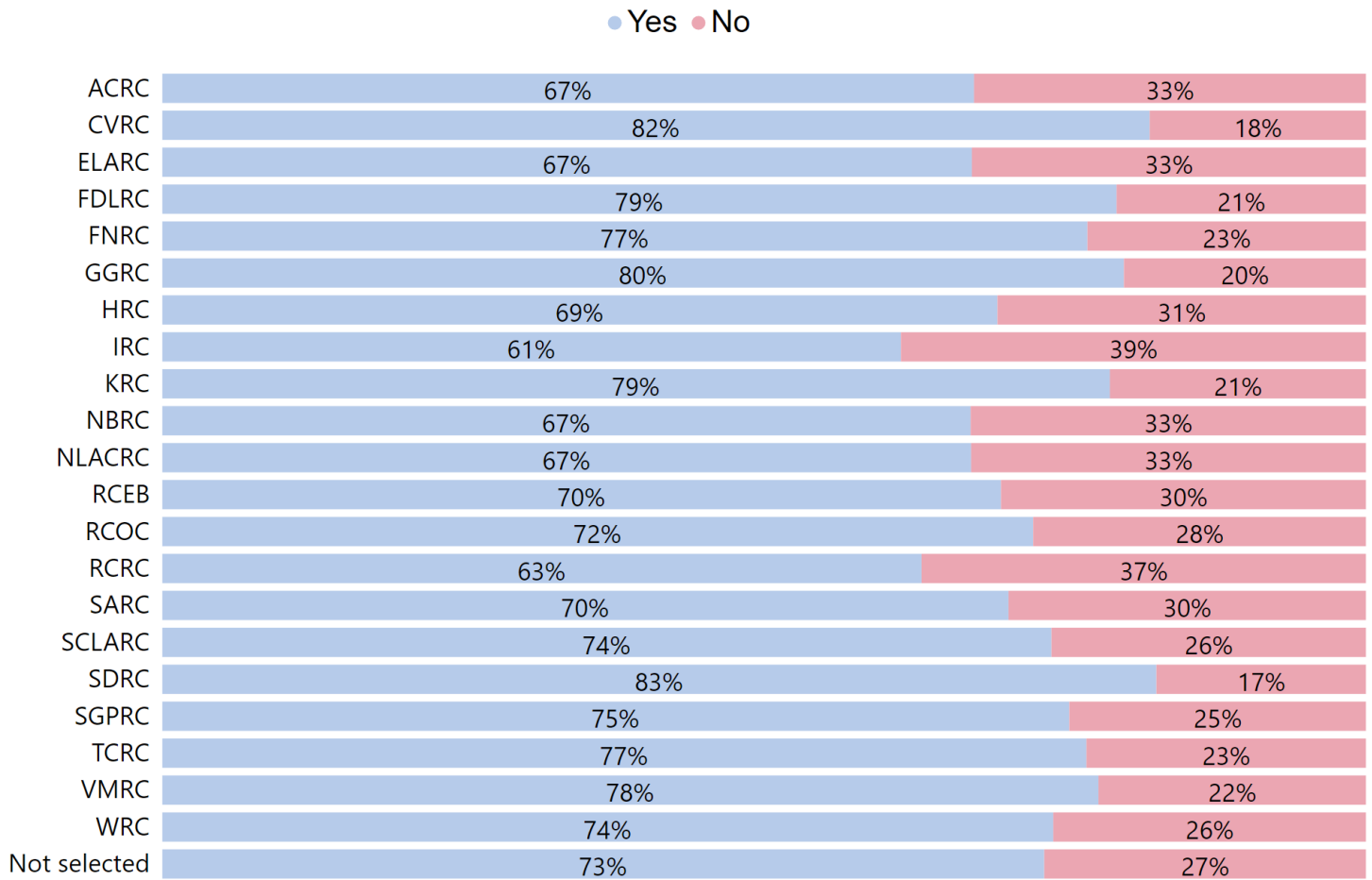
Respondents who identified as Other ethnicity were most likely to say that they have not received services they need from their regional center (38%), followed by Pacific Islander respondents and those who preferred not to state their ethnicity (34%), Other Asian respondents (31%) and Hispanic respondents (28%). 24% of White and African American respondents said the same. (Figure 9a)

Figure 9a: Getting needed regional center support, by ethnicity



The percent of respondents who reported that they did not receive the supports they needed from their regional centers ranged from a high of 39% to a low of 17% by regional center. (Figure 9b)

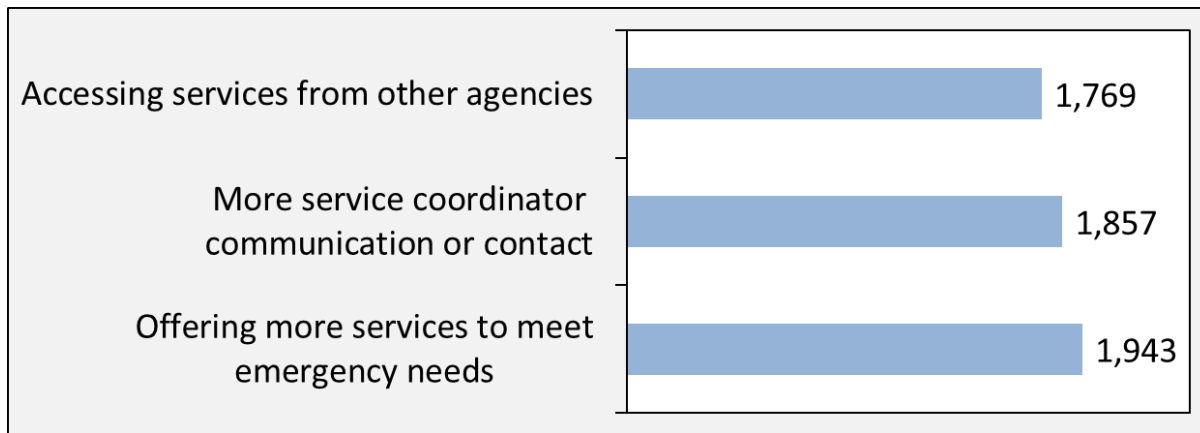
Figure 9b: Getting needed regional center support, by regional center



Some families would have liked additional types of supports.

Approximately one in five respondents would have liked help connecting with other agencies, having more contact with their regional center, or getting assistance with emergency needs. (Figure 10)

Figure 10: Additional needed supports



The most common amount of contact from regional centers was once or twice from March through November/December 2020.

Four of every 10 respondents said their regional center had contacted them one or two times by the time they submitted their survey. Approximately one-quarter had been contacted three or four times, and another quarter had been contacted five or more times. One out of 10 reported that their regional center had never reached out to them. (Figure 11)

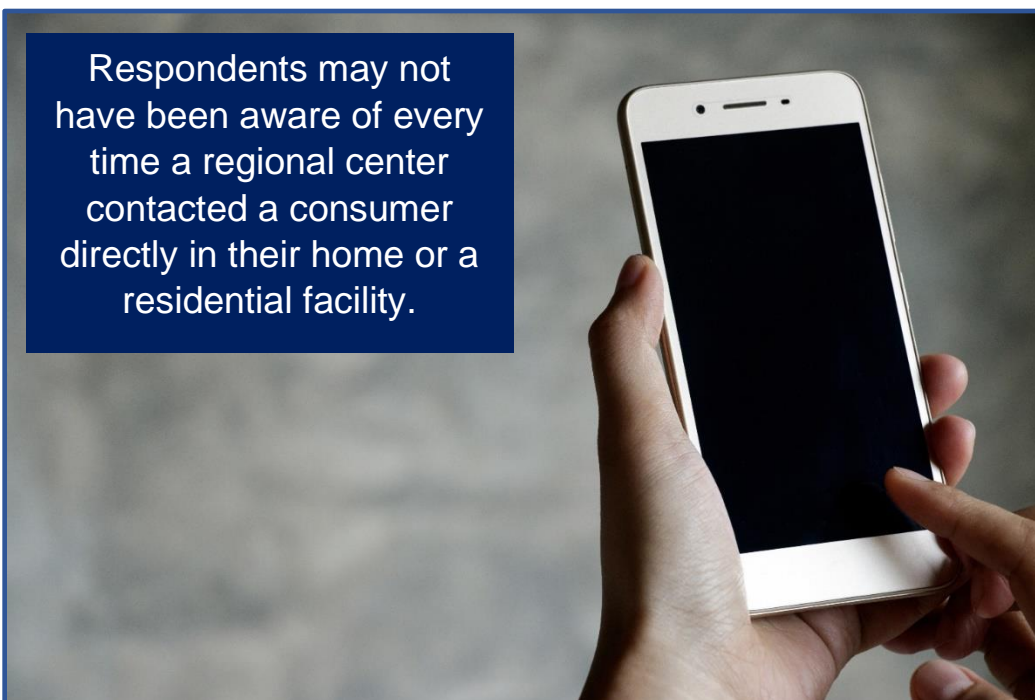
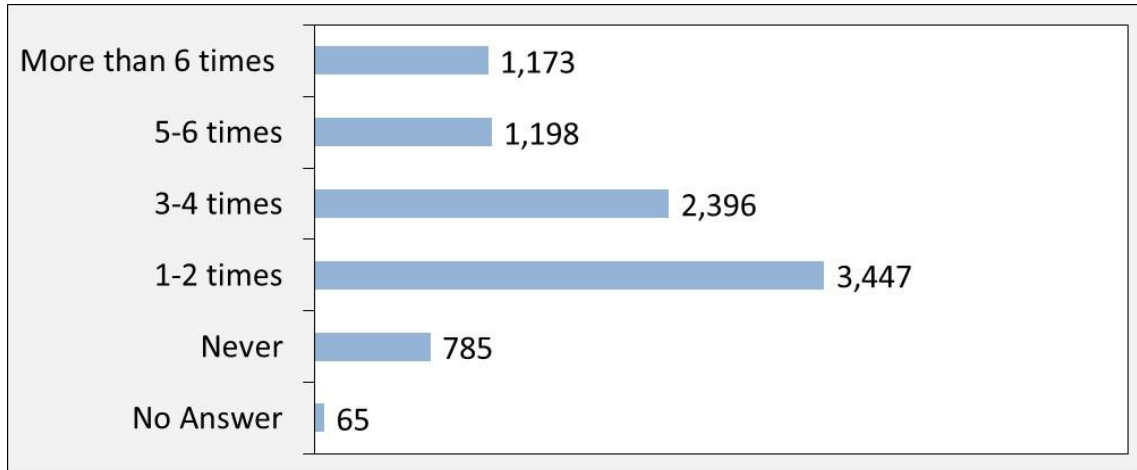


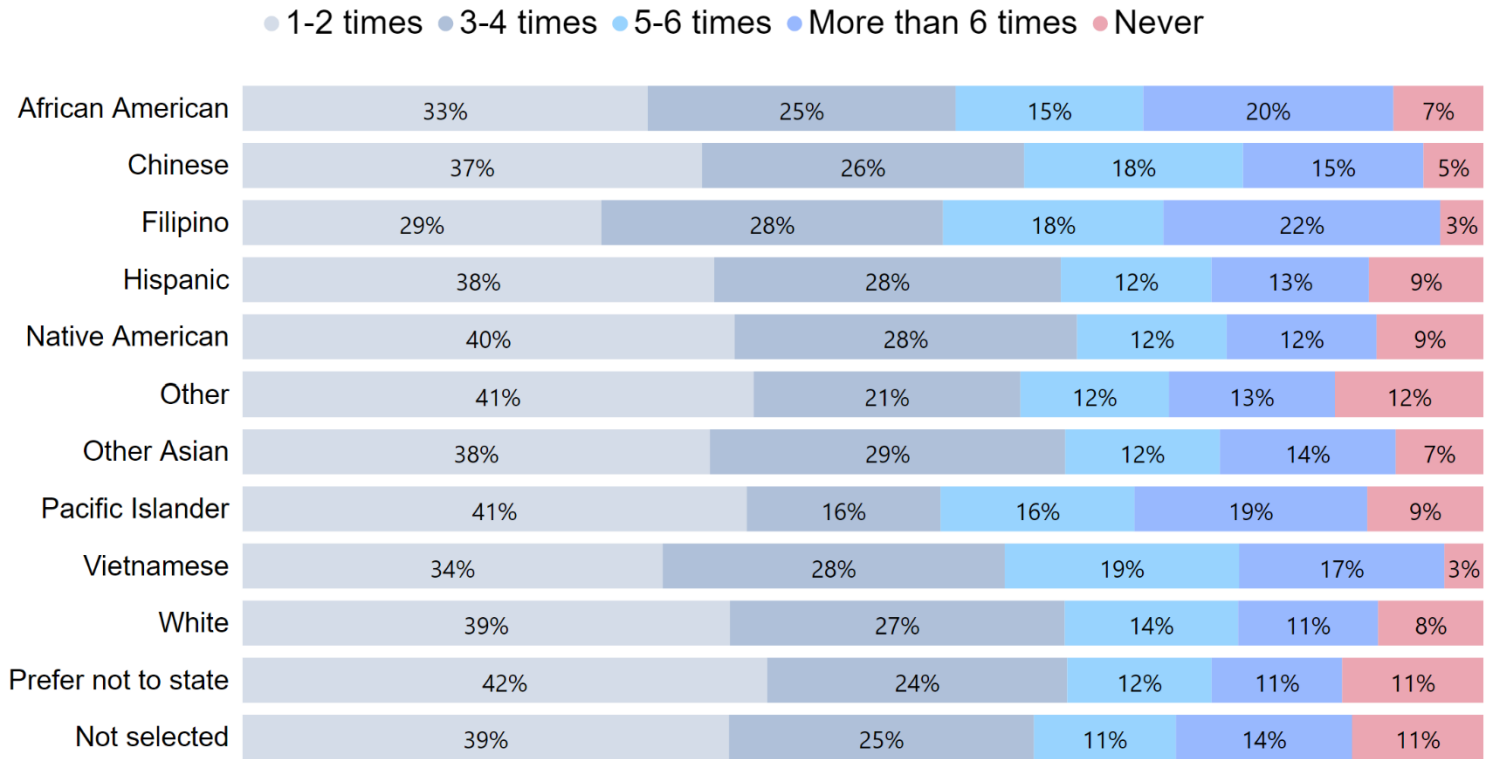
Figure 11: Number of contacts from regional center



In each ethnic community, 24% of respondents reported that their regional center contacted them five or more times during the COVID-19 pandemic. An additional 16% or more respondents from each ethnic community reported being contacted three or four times. (Figure 11a)

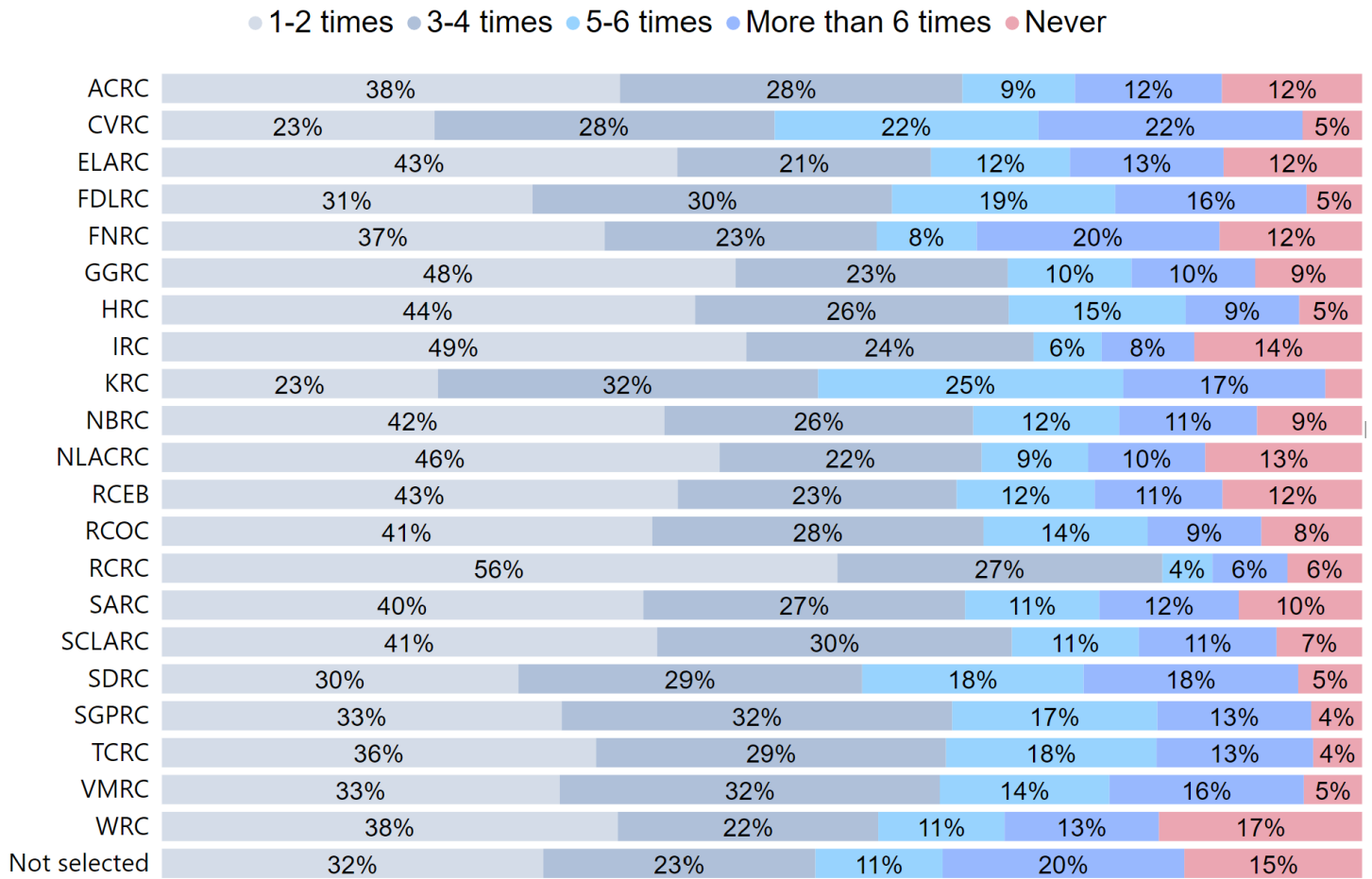


Figure 11a: Number of contacts from regional center, by ethnicity



During the COVID-19 pandemic, respondents reported that, by regional center, at least 37% received three or more contacts. (Figure 11b)

Figure 11b: Number of contacts from regional center, by regional center



Most respondents had enough contact from their regional center.

74% of survey respondents said the amount of outreach from their regional center was adequate for their needs. 24% said it was not, and 2% did not answer this question. (Figure 12)

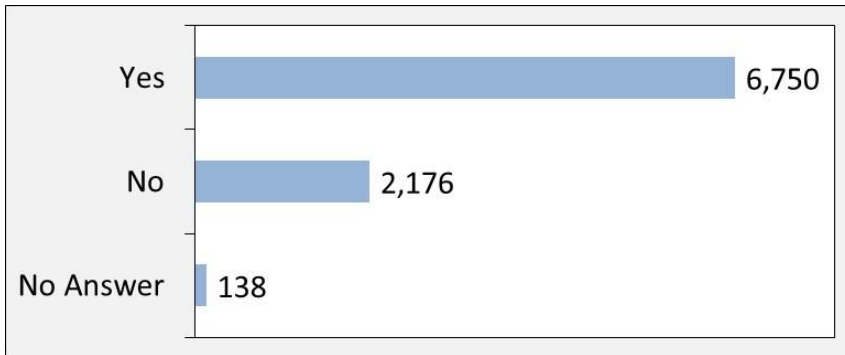
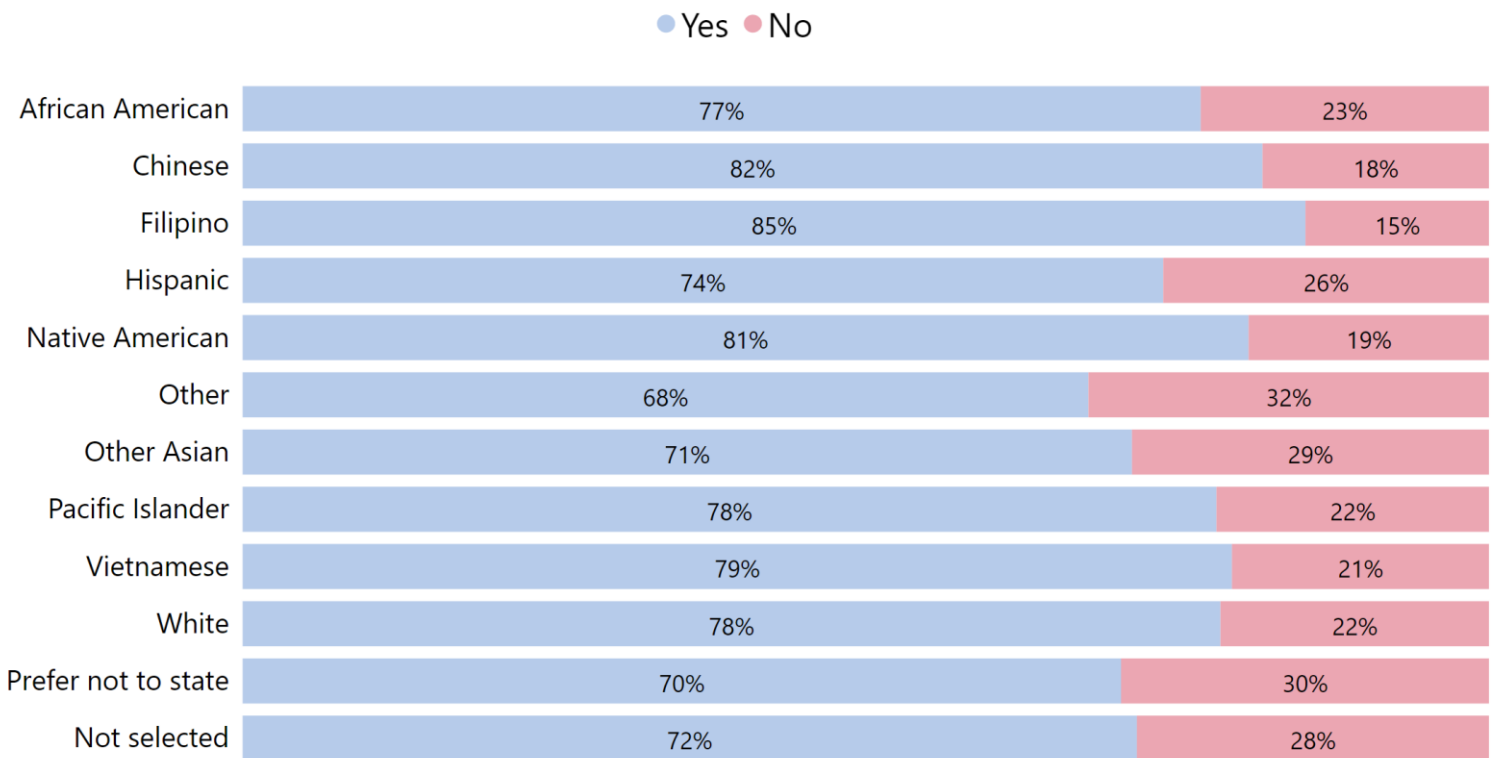


Figure 12: Regional center contact met needs

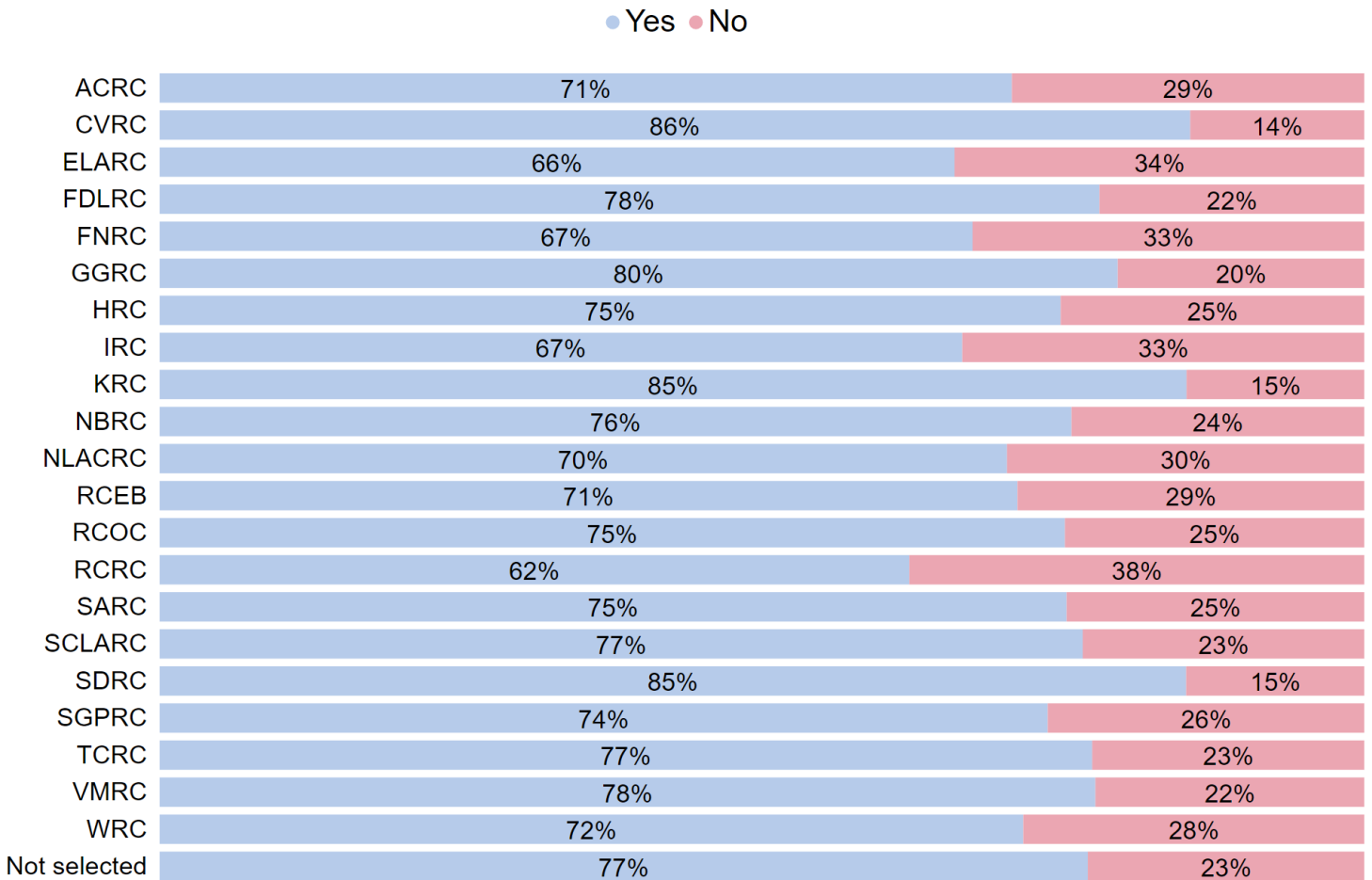
Filipino respondents were most likely to say that outreach from their regional center was adequate for their needs (85%), followed by Chinese (82%) and Native American respondents (81%). Of the remaining ethnicities, at least 68% reported that their contact needs were met. (Figure 12a)

Figure 12a: Regional center contact met needs, by ethnicity



In the majority of regional centers at least two out of three respondents stated that regional center contacts during the pandemic met their needs. (Figure 12b)

Figure 12b: Regional center contact met needs, by regional center



3:3 Satisfaction with Service Provider

Most respondents were satisfied with their service provider.

Among those answering this question, more than eight out of 10 were satisfied with their service provider during the pandemic. Fewer than two of every 10 were not satisfied. (Figure 13)

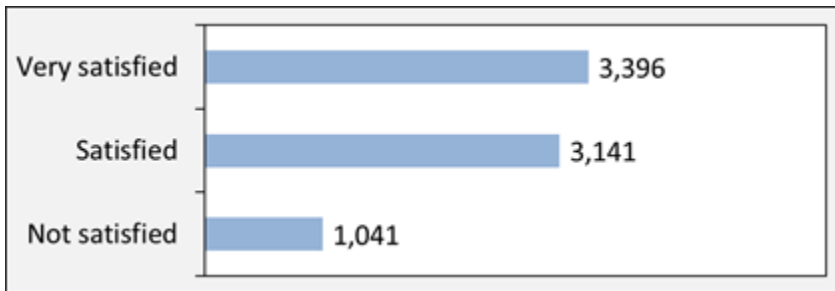
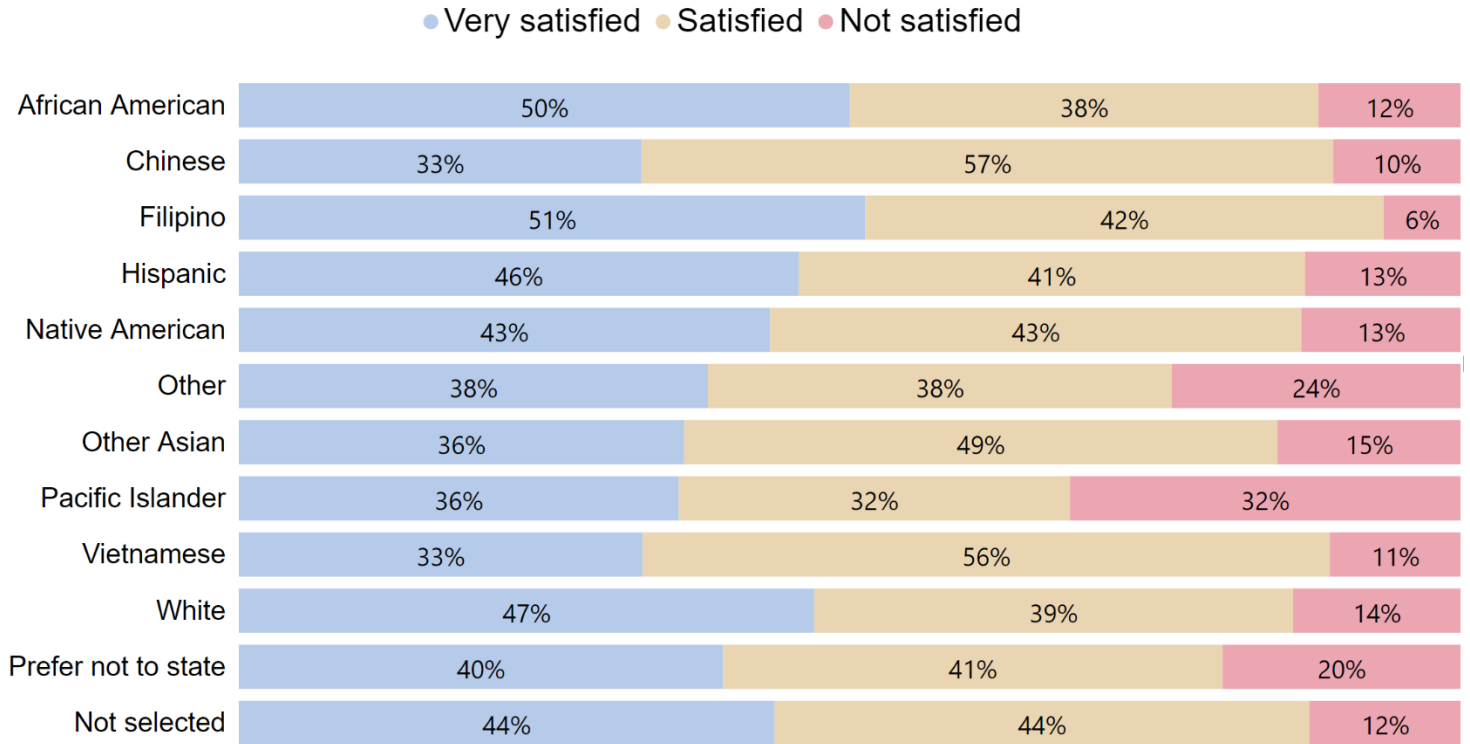


Figure 13: Satisfaction with service provider

Approximately nine out of ten Filipino (93%) and African American respondents (88%) stated that they were satisfied with the services received from their service provider. More than 80% of respondents from every ethnic community except Pacific Islanders and Other reported being satisfied with their service provider during the pandemic. (Figure 13a).

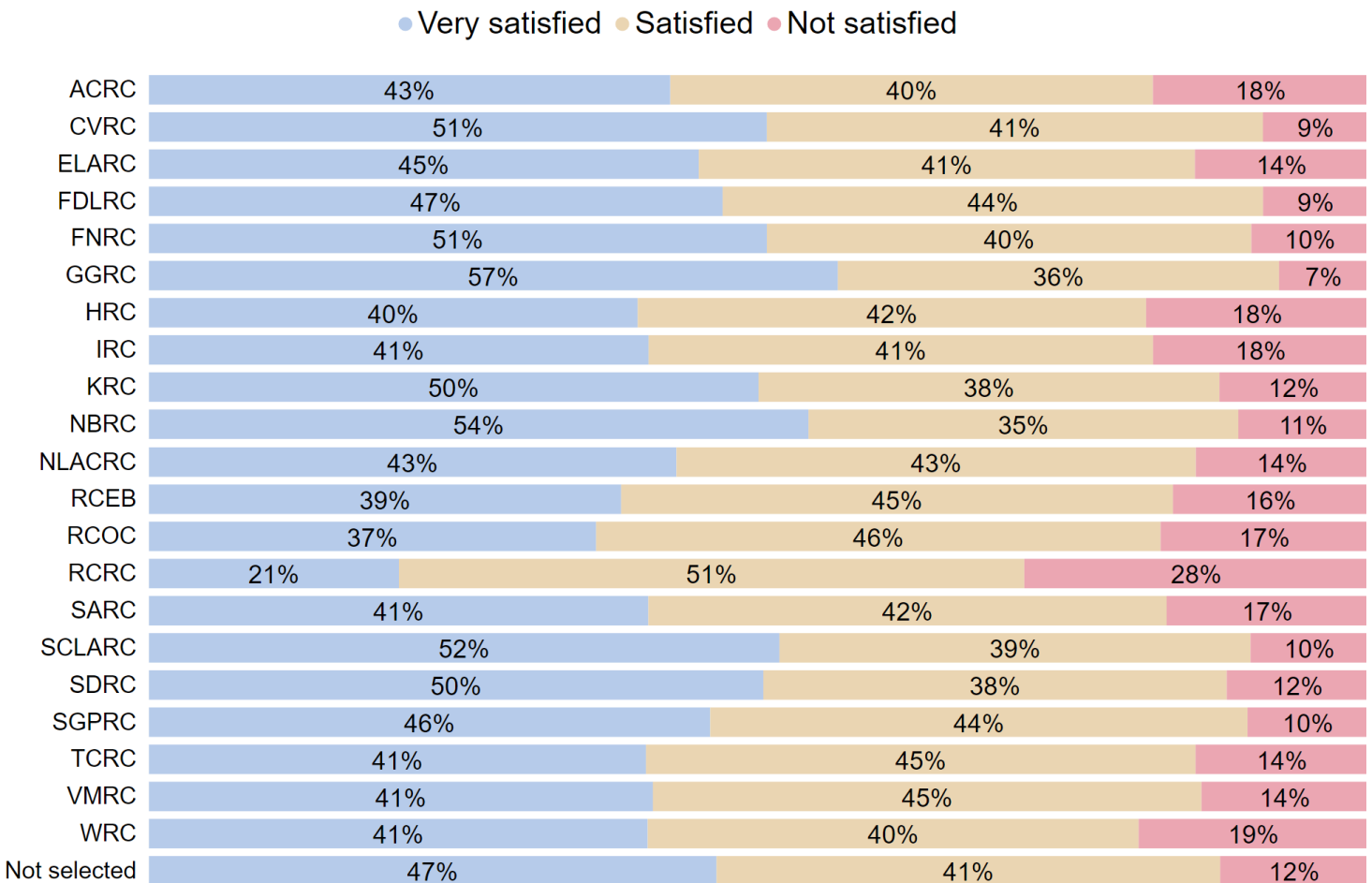


Figure 13a: Satisfaction with service provider, by ethnicity



In nearly all regional centers more than 80% of respondents stated that they were satisfied with their service provider during the pandemic. (Figure 13b)

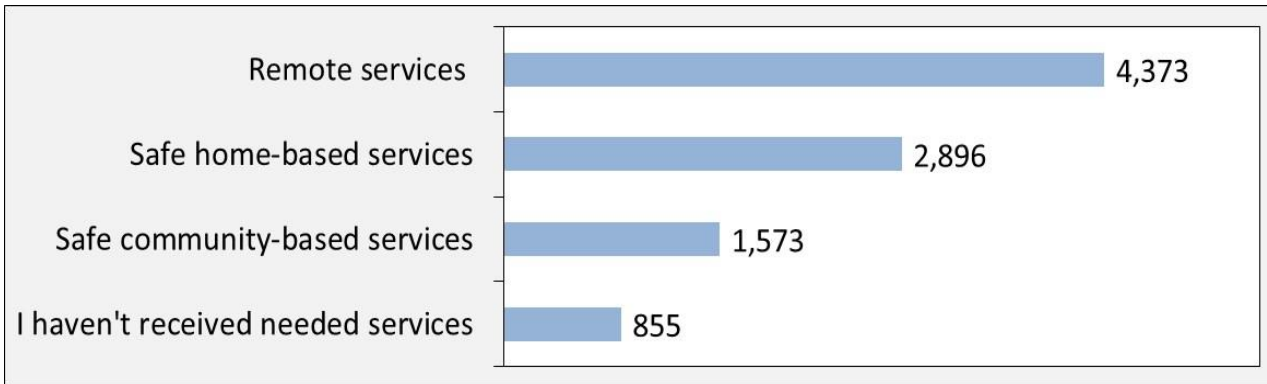
Figure 13b: Satisfaction with service provider, by regional center



Many survey respondents received remote and safely provided home- and community-based services during the pandemic.

Among families who have a service provider and answered this question, half received remote services, one-third received safely provided home services, and one in five received safely provided community-based services. However, one in 10 individuals answering this question did not receive the services or supports they needed. (Figure 14)

Figure 14: How services were delivered during the pandemic



Before the pandemic, remote services were not a typical part of service delivery models. Regional centers and service providers pivoted to this service delivery method when the pandemic began to help families maintain continuity of services.

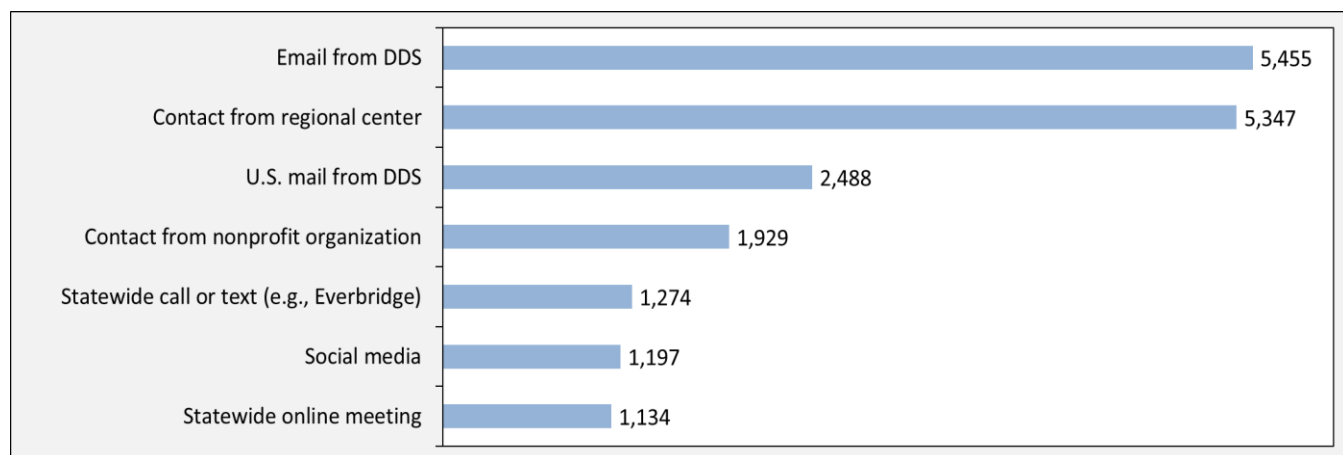


SECTION 4: PREFERRED CONTACT METHODS

Three out of five survey respondents said the best ways to provide them with information are through an email from DDS or outreach from their regional center (60% and 59%, respectively). Half as many prefer the U.S. Postal Service (28%). A statewide call, statewide online meeting, or social media work well for approximately one in eight respondents (14%, 13%, and 13%, respectively). (Figure 15)

Respondents were able to select more than one response to this question. This survey was conducted online. Respondents who took the online survey may generally prefer online activities. Some regional centers provided information in newsletters, which was not a response option in the survey.

Figure 15: Preferred ways to receive information



Contact DDS

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