2019-2020 NCI® Adult Family Survey

Family Report

Regional Center of the East Bay





This report tells us:



The services you receive



Satisfaction with the services



Activities in the community

Making Connections – Why is This Important?

Many adults with intellectual and developmental disabilities (IDD) who get services and supports live with their families. National Core Indicators (NCI) data tells us that across states 2 out of 5 people with IDD live with their family. In California there are over 90,000 adults who live with their family.

This report summarizes findings from the Adult Family Survey (AFS), which is sent to families who live with their adult relative with IDD. It is important to know if people and their families – like parents or siblings – are getting their needs met. This information can be shared with state officials (like a governor or regional centers) and policy makers. If they know when needs are not being met, they can try to find resources to help. This report gives families a way of letting state officials and policy makers know what is working for them and what is not working.



"Individuals like you"



In this report when we say "individuals like you" we mean the person who is getting services from the regional center who is over 18 and lives with their family.

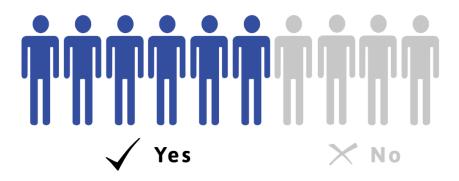
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Information about Services and Supports

Services are things the regional center helps organize. It is important that people who help plan services for you have information to help them make choices that are right for you and your family.

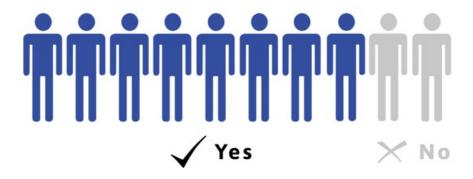


6 out of 10 families said they got enough information to help plan services.





8 out of 10 families said the information they got about services was easy to understand.

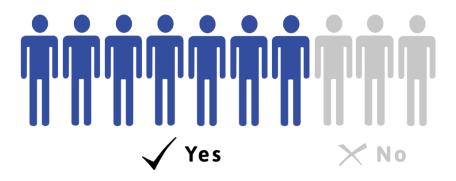


Service Planning

People who get services from a regional center have an individual program plan (IPP). The IPP is a list of services your service coordinator helps you and your family get.

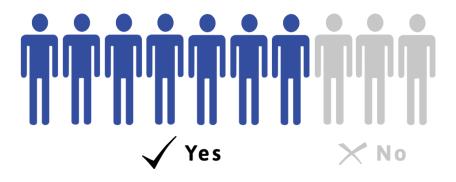


7 out of 10 families said the IPP included all the services and supports needed.



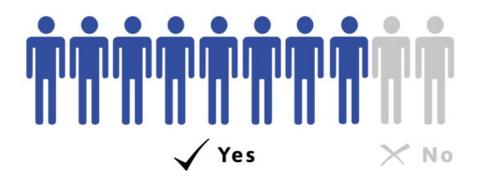


7 out of 10 families said all the services listed in the IPP were received.



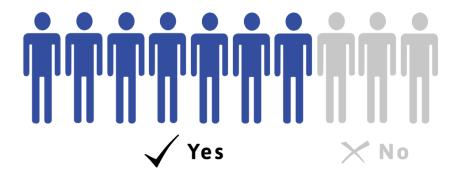


8 out of 10 families said they or someone else in their family (other than individuals like you) helped make the



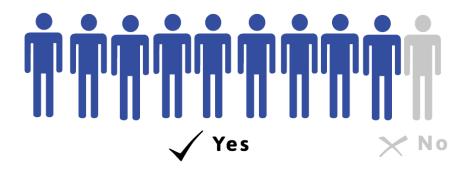


7 out of 10 families said individuals like you helped make the IPP.



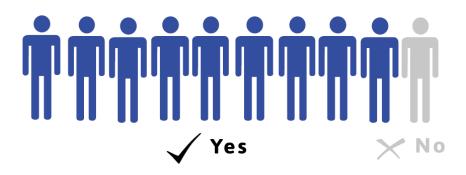


9 out of 10 families said the information from the regional center was offered in their preferred language.





9 out of 10 families said they received a copy of the IPP in their family's preferred language.

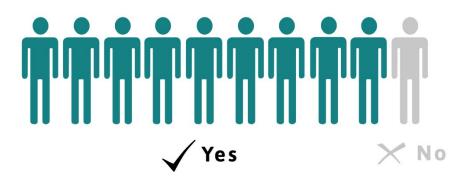


Access to Healthcare Services

Healthcare professionals are people like doctors, dentists, counselors and psychologists. It is important for people to be able to see healthcare professionals so they can stay healthy.

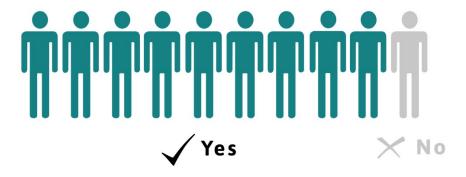


9 out of 10 families said individuals like you could see health professionals when they needed to.



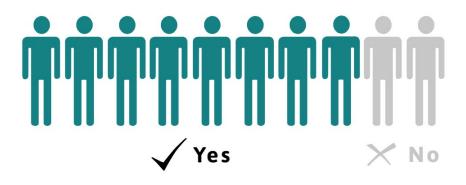


9 out of 10 families said primary care doctors understood disability-related needs for individuals like you.



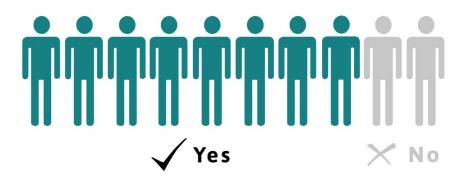


8 out of 10 families said individuals like you could go to the dentist when they needed to.



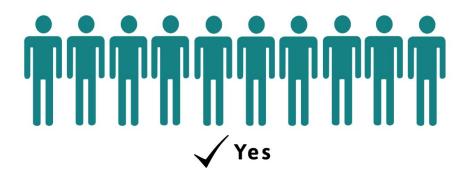


8 out of 10 families said dentists understood disability-related needs for individuals like you.





10 out of 10 families said they knew what medications were for if medication was taken.



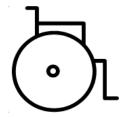


5 out of 10 families who needed respite services were able to use them.

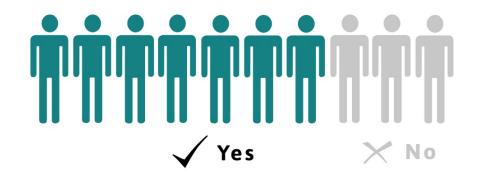


Access to Needed Services

It is important you get the different kinds of services and supports you need.

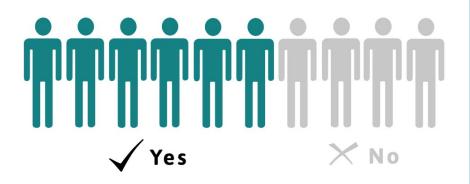


7 out of 10 families said individuals like you had the special equipment or accommodations they needed.





6 out of 10 families got the supports and services they needed.



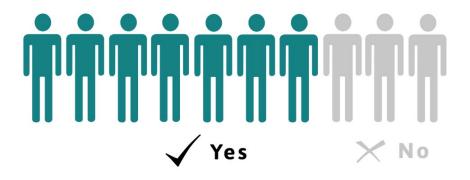


Satisfaction with Services and Supports

It is important that you are happy with the services you get.

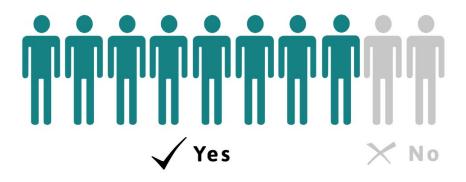


7 out of 10 families said that overall, they were happy with services and supports.



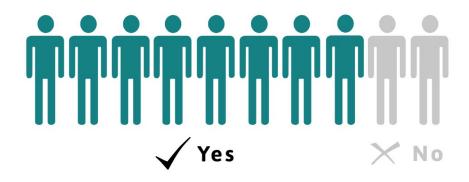


8 out of 10 families said services and supports have made a positive difference in the lives of individuals like you.



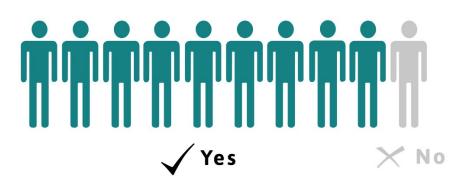


8 out of 10 families said services and supports helped individuals like you live a good life.



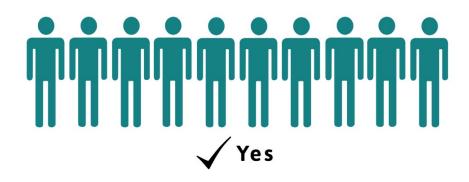


9 out of 10 families said there were support workers available who could speak their preferred language.



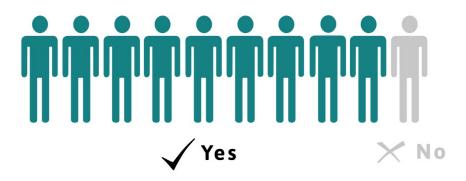


10 out of 10 families said their service coordinator spoke their preferred language.





9 out of 10 families said their service coordinator supported them in a way that was respectful to their culture.

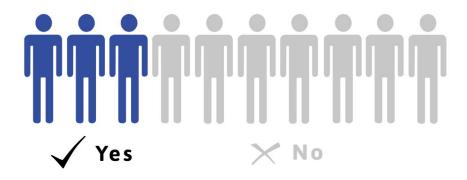


Crisis and Emergency Services

Sometimes emergencies like a medical emergency or natural disaster happen. It is important that you have the information you need to handle emergencies if they happen.

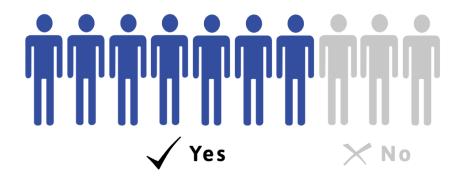


3 out of 10 families said they talked about how to handle emergencies at the last IPP meeting.





7 out of 10 families said they felt prepared to handle the needs of individuals like you in an emergency.

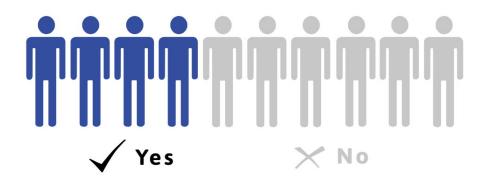




ness-toolkit



4 out of 10 families who asked for crisis or emergency services in the past year got services when needed.





Preparing for an Emergency



1 Get Alerts and Know your Support Team

2 Prepare an Emergency Supply Kit



3 Make an Emergency Evacuation Plan

4 Practice Your Plan

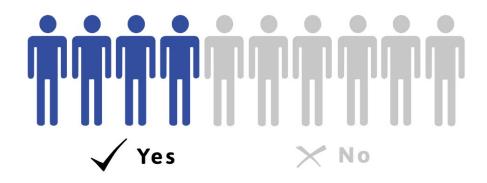
Visit the "Preparing for an Emergency" wellness bulletin at https://www.dds.ca.gov/consumers/wellness-toolkit/self-advocates for more information.

Complaint Filing

If something bad happens, it is important to know who to talk to.

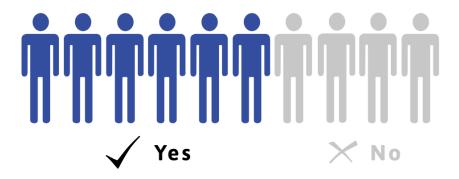


4 out of 10 families said they knew how to file a complaint or grievance about provider agencies or staff.





6 out of 10 families said they knew how to report abuse or neglect.

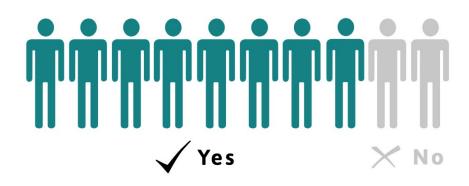


Going Out

People go out in their community to do many things. You may like to go to the movies, concerts, or play sports. When we ask about community, we mean the places close to home where you and other people go out.



8 out of 10 families said that individuals like you took part in activities in the community.



Challenges to Community Involvement

Although most individuals participated in community activities, some still found challenges to community involvement. Some challenges were:



Stigma 1 out of 10



Cost 2 out of 10



Lack of **Transportation** 2 out of 10



Lack of **Support Staff** 2 out of 10

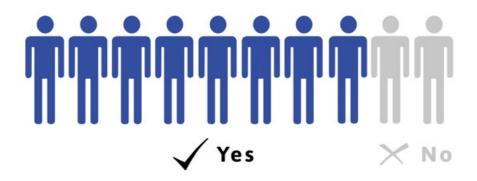
Overall, challenges were not preventing most individuals from participating in the community.

Service Coordinators and Support Workers

There may be many people who help you and your family. Service coordinators work closely with your family to help them decide, organize, and get the services you need. Support workers are paid to help you at home, at work, and at your day program.

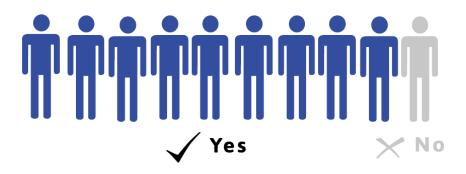


8 out of 10 families said they were able to contact their service coordinator when they wanted.



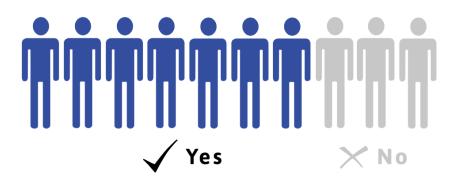


9 out of 10 families said the service coordinator respected their family's choices and opinions.



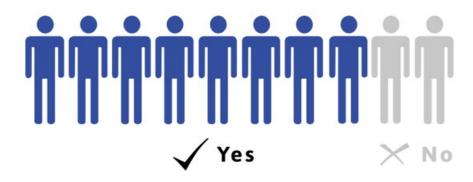


7 out of 10 families said they were able to contact support workers when they wanted.



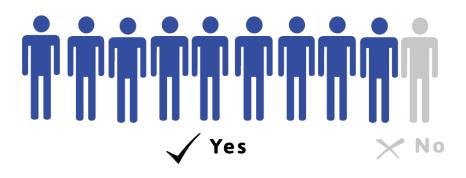


8 out of 10 families said support workers came and went when they were supposed to.



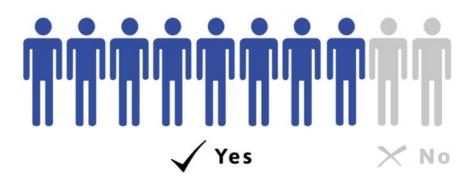


9 out of 10 families said support workers spoke to them in a way they understood.



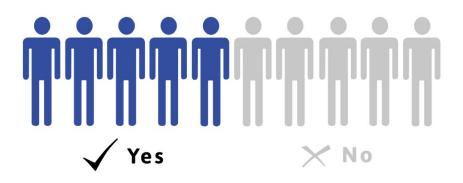


8 out of 10 families said support workers had the right information and skills to meet their family's needs.



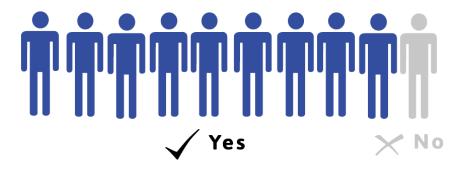


 $\boldsymbol{5}$ out of $\boldsymbol{10}$ families said providers worked together to provide support.





9 out of 10 families said services were delivered in a way that was respectful of the family's culture.



What is NCI?

Each year, National Core Indicators (NCI) asks people with intellectual and developmental disabilities (IDD) and their families how they feel about their lives and the services they get. NCI uses surveys so that the same questions can be asked to people in all NCI states.

Who answered questions to this survey?

Questions for this survey are answered by a person who lives in the same house as an adult who is getting services from the regional center. Most of the time, a parent answers these questions. Sometimes a sibling or someone who lives with the person and knows them well answers these questions.



How are data shown in this report?

We use words and images to show the number of yes and no answers we got. Some of our survey questions have more than a yes or no answer. They ask people to pick: "always," "usually," "sometimes," or "seldom/never." For this report, we count all "always" and "usually" answers as a yes. All others we count as no.







View the NCI Interactive Dashboards

https://www.dds.ca.gov/rc/nci



View Self-Advocate Wellness Bulletins

https://www.dds.ca.gov/consumers/wellness-toolkit/self-advocates



Find NCI Regional Center Liaisons

https://www.dds.ca.gov/rc/nci



Find Regional Center Information

https://www.dds.ca.gov/rc

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