

2019-2020 NCI® Family Guardian 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?

When family members with IDD move out of their family homes, parents and other family members continue to be concerned about their well-being and whether their needs are being met. National Core Indicators (NCI) data tells us that across states 3 out of 5 people with IDD live in a supported setting. In California there are over 30,000 adults who live independently or in a supported setting.

This report summarizes findings from the Family Guardian Survey (FGS), which is sent to families of adults who live independently or in a supported setting. It is important to know if families – like parents or siblings – believe their family member is getting needed support from staff and their service coordinator. 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 independently or in a supported setting.



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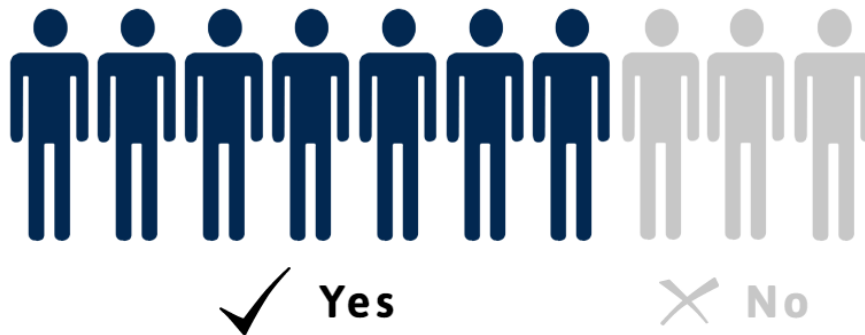
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Information about Services and Supports

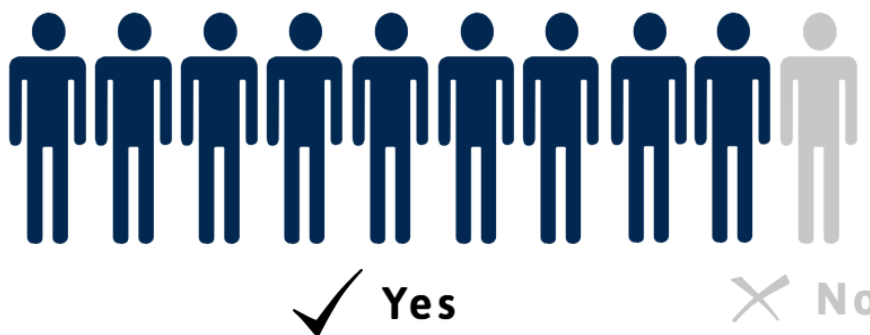
Services are things the regional center helps organize. It is important that people who help plan services for you have information to help them make choices that are right for you and your family.



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



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

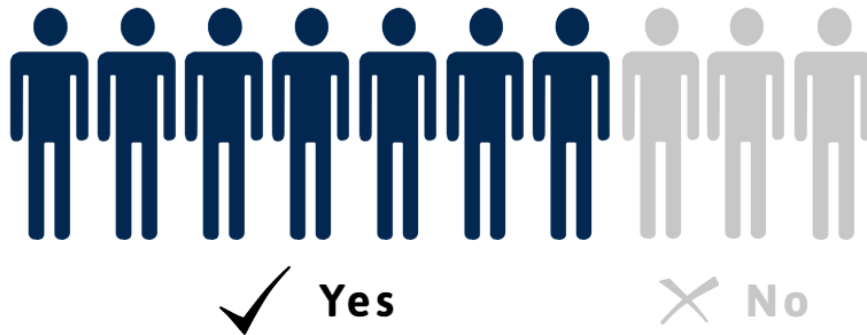


Service Planning

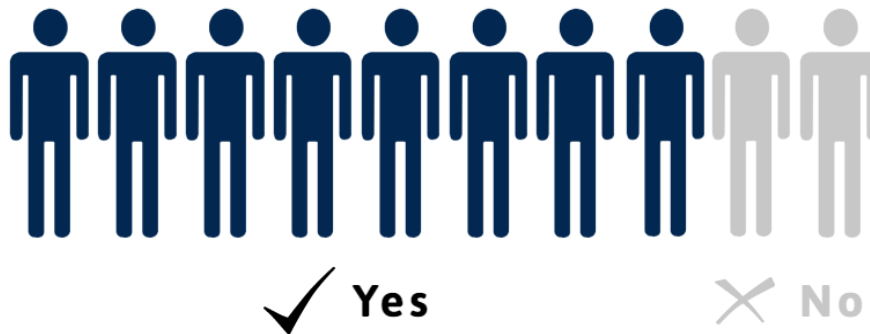
People who get services from a regional center have an individual program plan (IPP). The IPP is a list of services your service coordinator helps you and your family get.



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

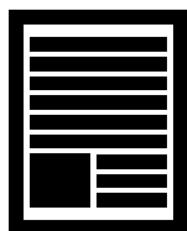
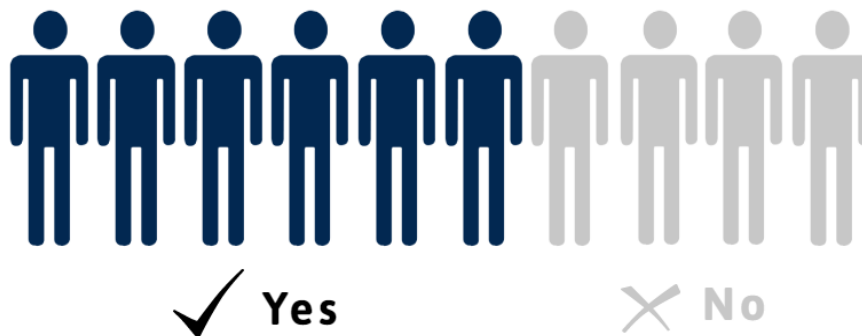


8 out of **10** families said **all the services listed in the IPP were received.**

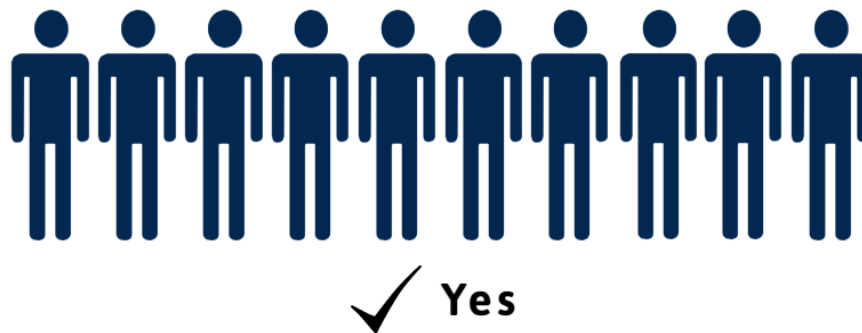




6 out of **10** families said **individuals like you** helped make the IPP.

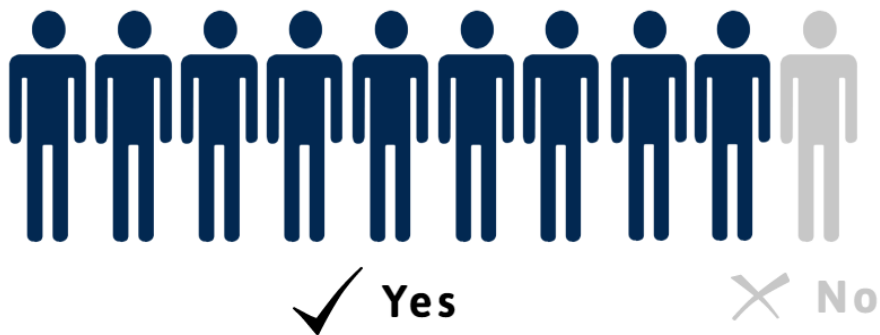


10 out of **10** families said **the information from the regional center** was offered in their preferred language.





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.**



✓ Yes

✗ No

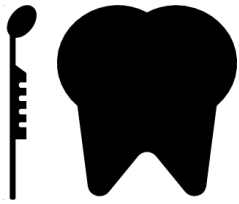


8 out of **10** families said **primary care doctors understood disability-related needs for individuals like you.**

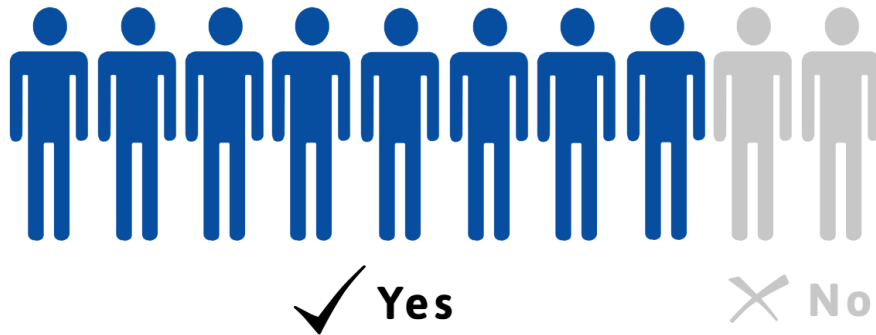


✓ Yes

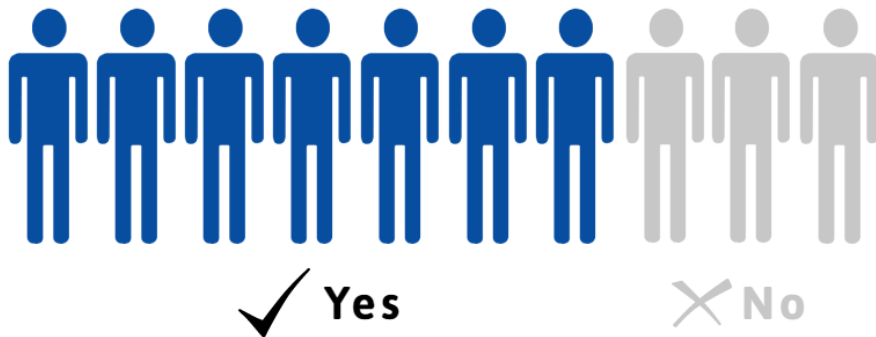
✗ No



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

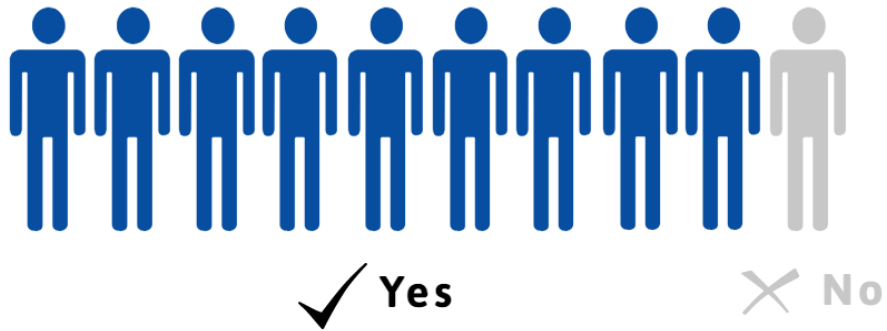


7 out of **10** families said **dentists understood disability-related needs for individuals like you.**



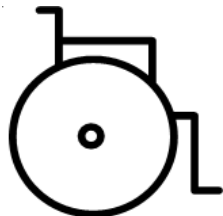


9 out of **10** families said **they knew what medications were for if medication was taken.**

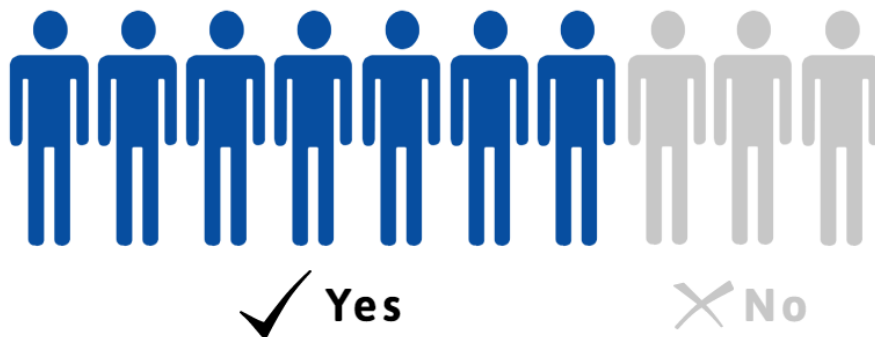


Access to Needed Services

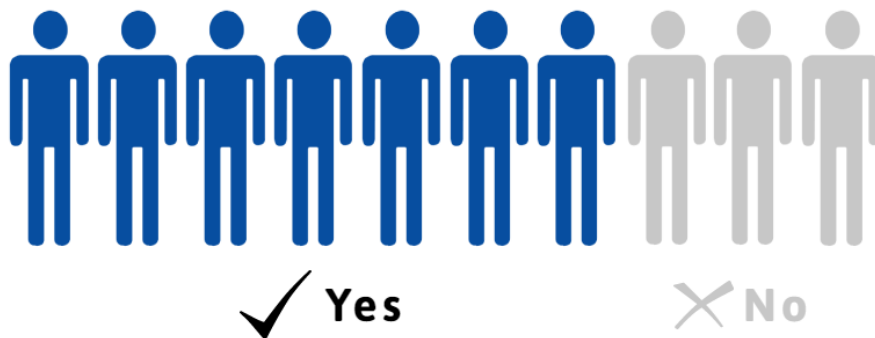
It is important you get the different kinds of services and supports you need.



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



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



Visit the **NCI Interactive Dashboards** on the DDS website to learn more about the services and supports needed.

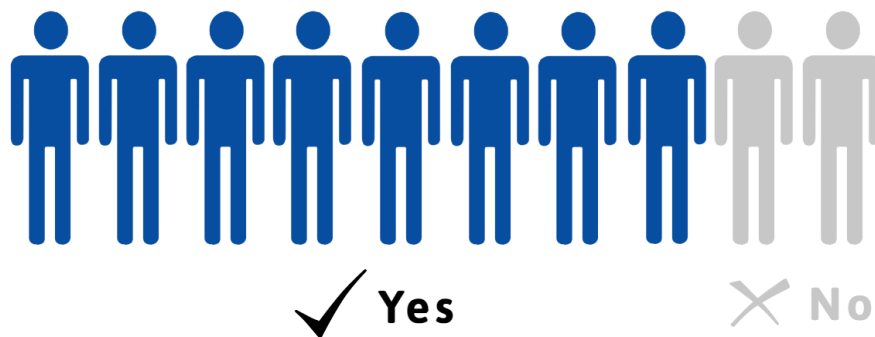
<https://www.dds.ca.gov/rc/nci>

Satisfaction with Services and Supports

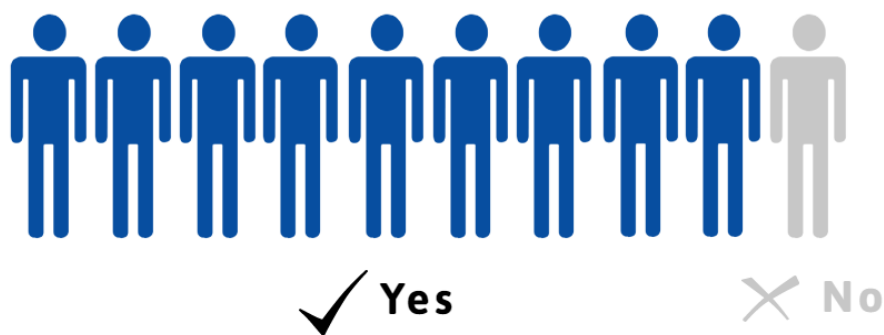
It is important that you are happy with the services you get.



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

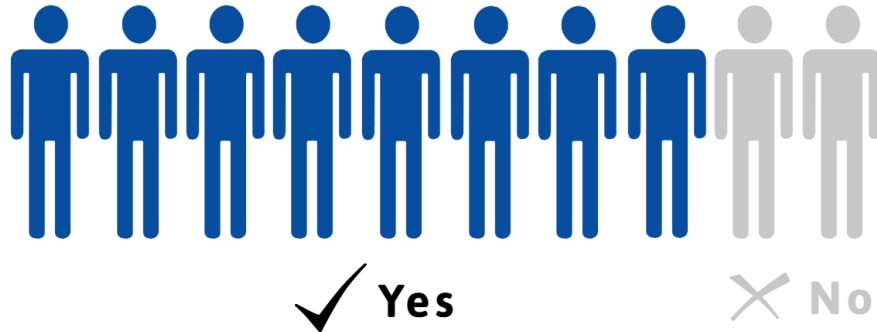


9 out of **10** families said **services and supports have made a positive difference in the lives of individuals like you.**

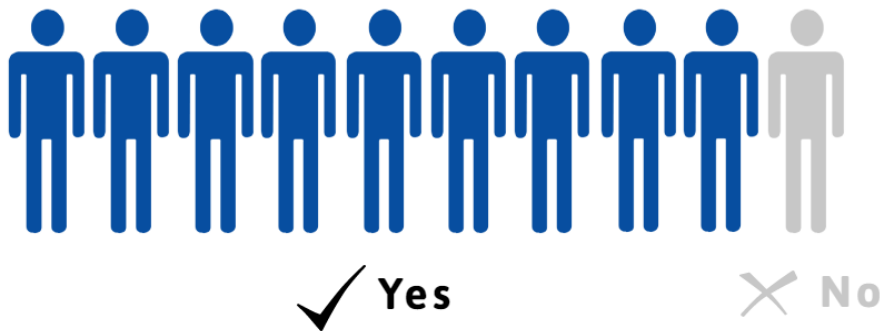


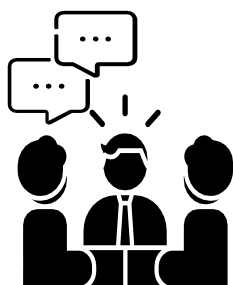


8 out of **10** families said **services and supports helped individuals like you live a good life.**

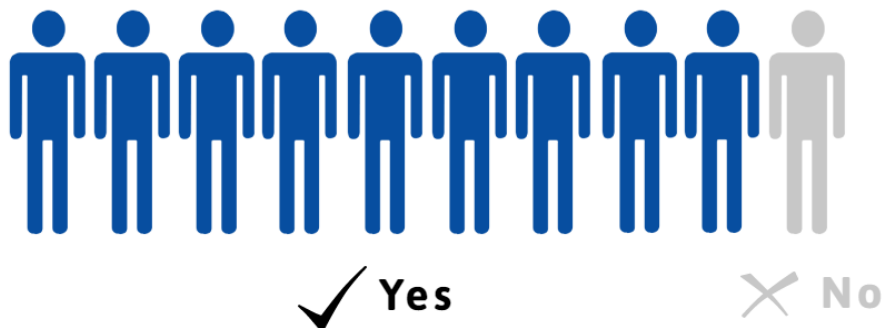


9 out of **10** families said **there were support workers available who could speak their preferred language.**

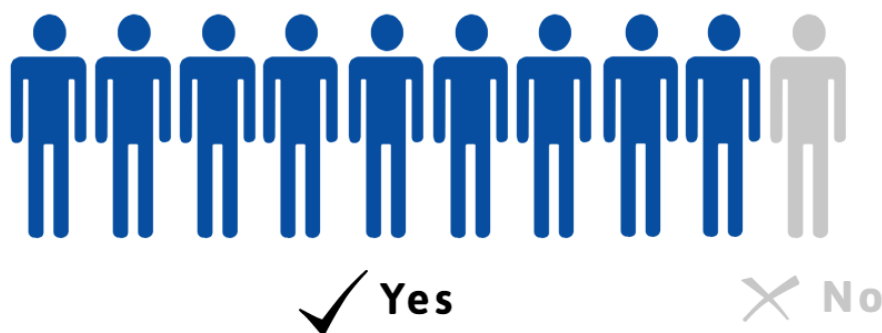




9 out of **10** families said **their service coordinator spoke their preferred language.**



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

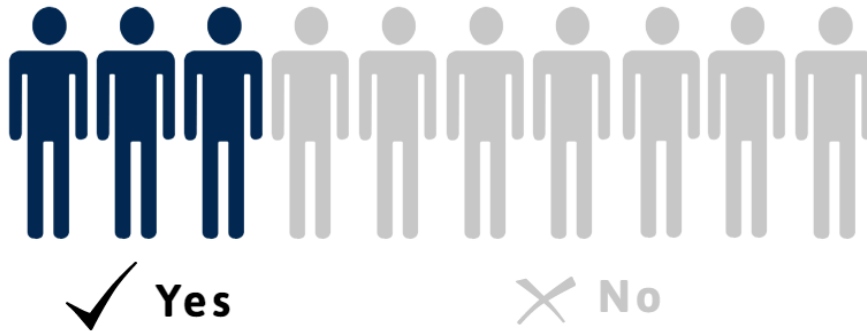


Crisis and Emergency Services

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.**



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



Visit the **Wellness Toolkit** on the DDS website for information and tools related to health and safety.

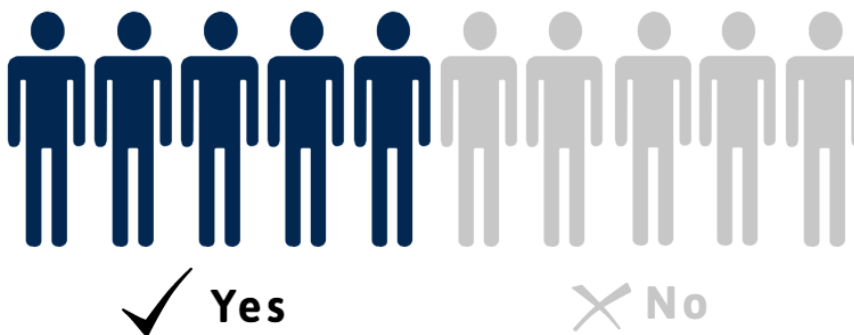
 <https://www.dds.ca.gov/consumers/wellness-toolkit>

Complaint Filing

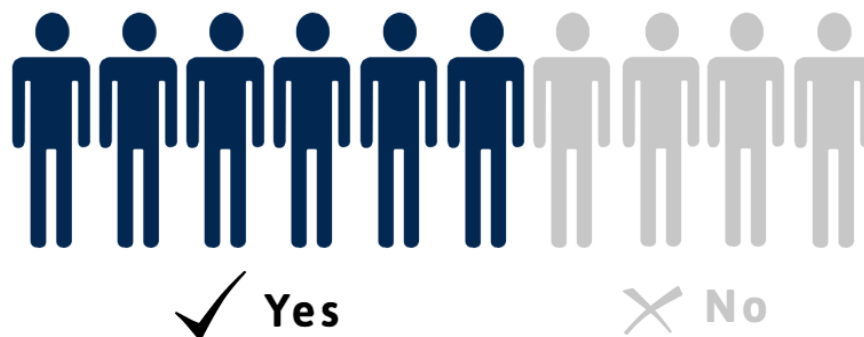
If something bad happens, it is important to know who to talk to.



5 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.**

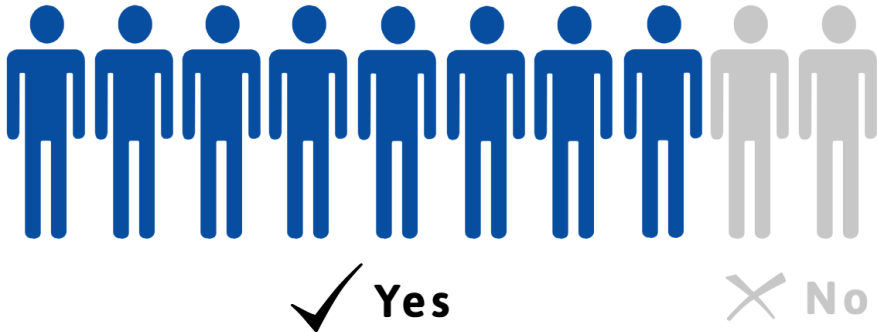


Going Out

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

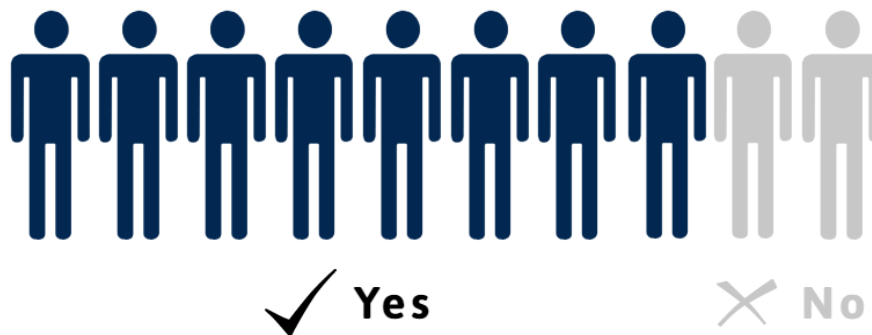
Overall, challenges were not preventing most individuals from participating in the community.

Service Coordinators and Support Workers

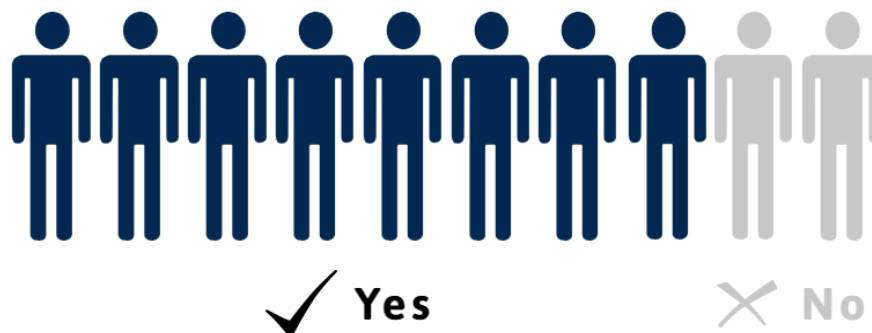
There may be many people who help you and your family. Service coordinators work closely with your family to help them decide, organize, and get the services you need. Support workers are paid to help you at home, at work, and at your day program.



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

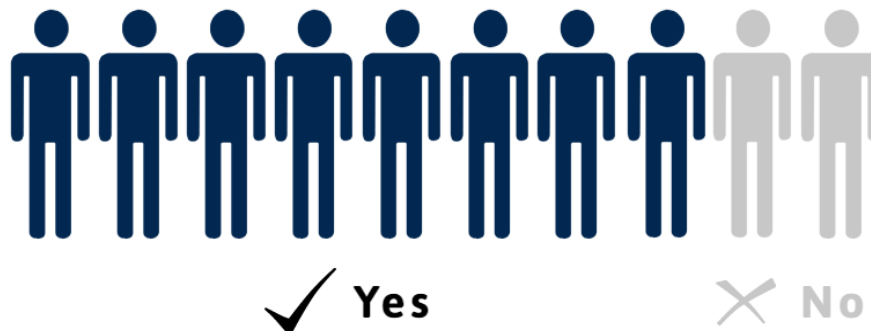


8 out of **10** families said **the service coordinator respected their family's choices and opinions.**

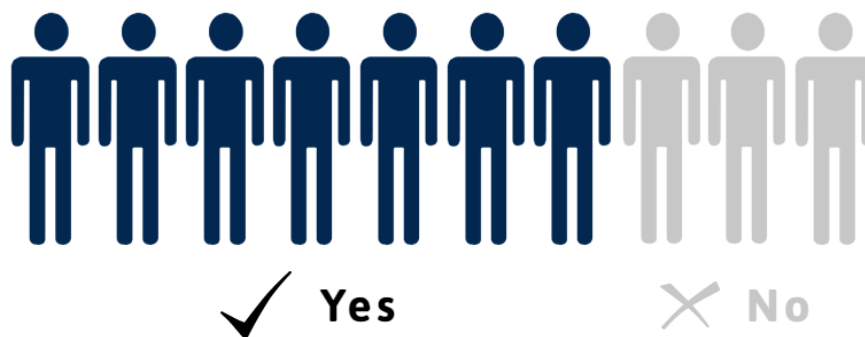




8 out of **10** families said they were able to contact support workers when they wanted.

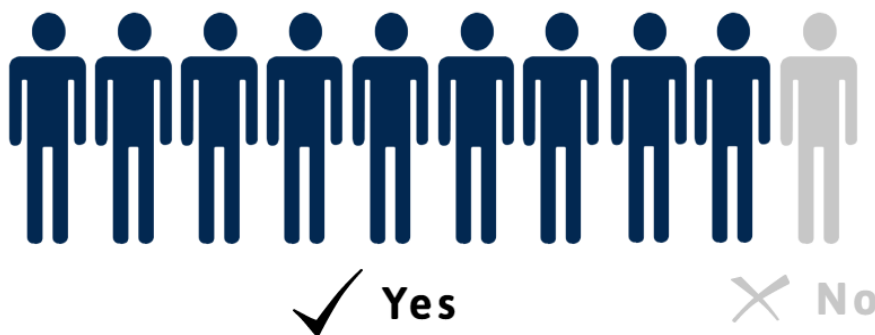


7 out of **10** families said support workers came and went when they were supposed to.

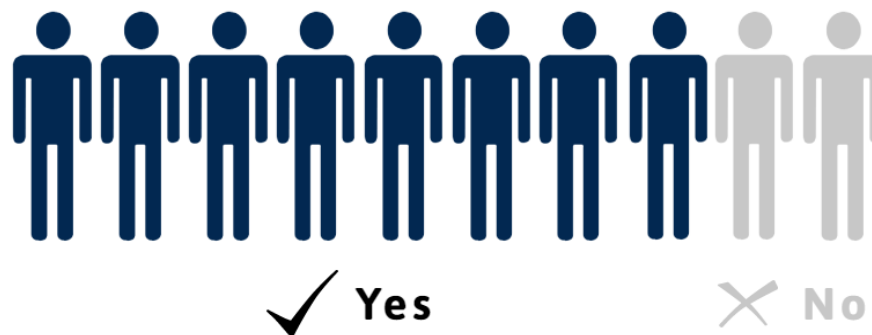




9 out of **10** families said **support workers spoke to them in a way they understood.**

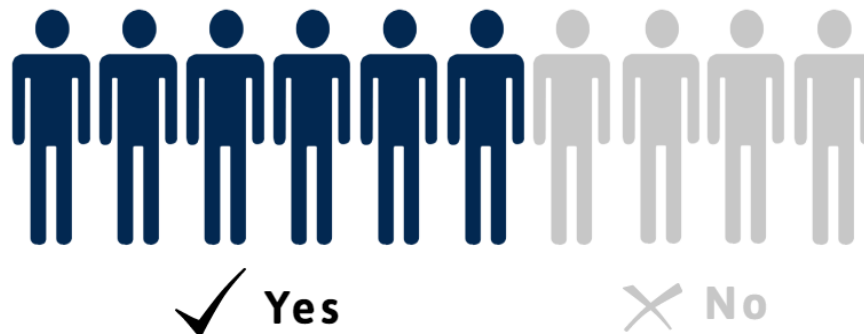


8 out of **10** families said **support workers had the right information and skills to meet their family's needs.**

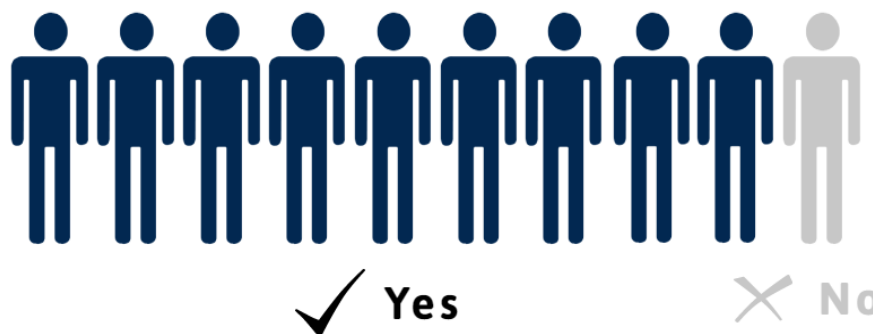




6 out of **10** families said **providers worked together to provide support.**



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



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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 family member or legal guardian - usually a parent or sibling - of an adult with IDD who lives independently or in a supported setting.



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.





Learn More



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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Have questions or comments? Email us at: ncihelp@dds.ca.gov