



ADDPC Survey Results

A unique survey of the Arizona I/DD community

February 2024

Topics

- ❖ Survey Review: Who we interviewed, what we asked, and why
- ❖ The Respondents: Who took the survey
- ❖ Branch One: Those who have NOT used behavioral crisis services
- ❖ Branch Two: Those who HAVE used behavioral crisis services
- ❖ Key Takeaways and Actionable Insights

Presented by...

Mike Noble
Founder & CEO, NPI

Survey Review

Recap of our goals, methods, and motivation

Project Goals

The Target Audience

- A very specific part of the overall population: members of the I/DD community
- Within that small community, cast a wide net: people with I/DD, family members, caregivers, professionals, and more

1

The Goal

- Understand the community's experience with behavioral healthcare and crisis response services
- Get feedback on the role played by the DDD when individuals sought assistance from behavioral health/crisis response

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The Challenge

- Craft a survey that lets two groups – those who HAVE and those who HAVE NOT used crisis services – report their experiences
- Hear people in their own words
- Get the survey to the community

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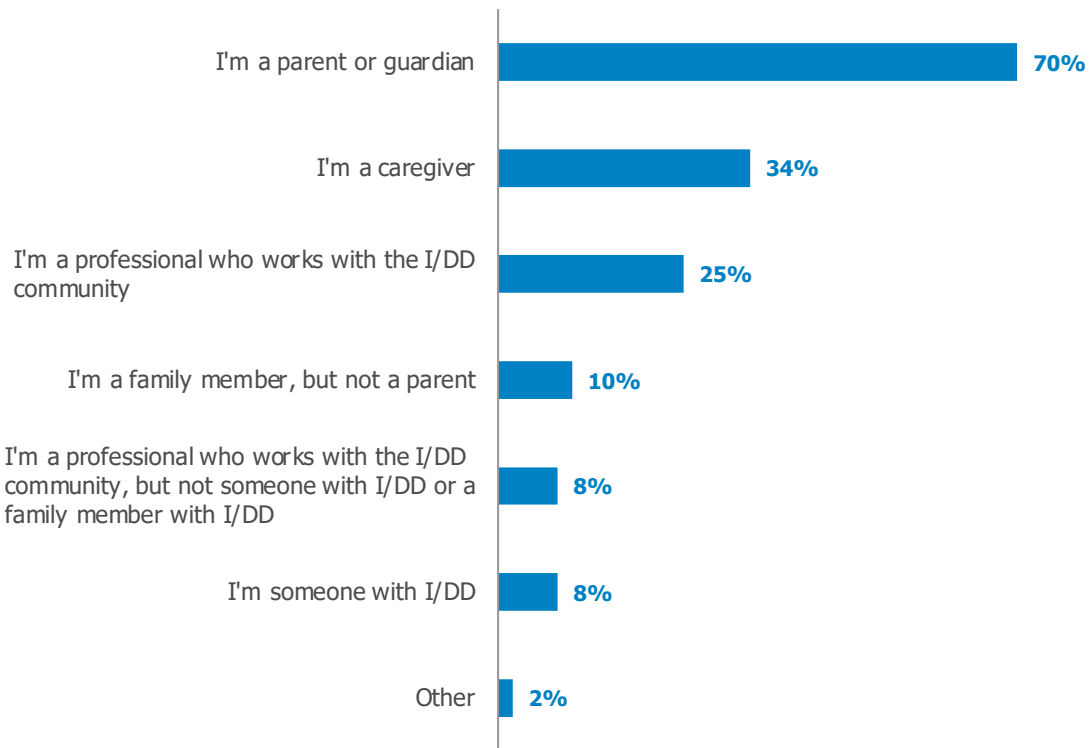
Meeting the Challenge – Finding the Right Respondents

- The target population for this survey – the I/DD community – is much smaller than a garden variety, general population survey.
- OHSC and our partners in the I/DD community circulated this survey through a wide variety of social media groups, email lists, and other digital channels.
- Respondent screen:
 - Reported living in Arizona
 - “Yes” to “Do you, a family member, or someone you provide care for have an intellectual or developmental disability? Examples include being on the autism spectrum, having Down Syndrome or Cerebral Palsy.”
 - If not, the survey ended
- **An excellent pool of respondents:**
 - **None were eliminated due to inattention, quality checks, or any other flag**
 - **Detailed answers to many free-response questions**
 - **Signs point to a strong sample**

Who We Interviewed: Role in the I/DD Community

- Respondents were given a list of ways they might be connected to or a part of the I/DD community. They were allowed to select ALL descriptions that applied to them.
- Many respondents were members of multiple communities – the survey had numerous parents, guardians, caregivers, professionals, and people with I/DD.

Which of the following best describes your relationship to the intellectual or developmental disabilities (I/DD) community? Please select all that apply.



Q) Which of the following best describes your relationship to the intellectual or developmental disabilities (I/DD) community? Please select all that apply. (Total Respondents N=178).

† Note: Some numbers (on the chart or elsewhere) may not appear to be totaled correctly. This is due to rounding.

Respondents: A Demographic Breakdown

A diverse sample in every way: race, gender, region, education, and age.

Some demographics may not add up to the overall sample size, as respondents were allowed to refuse to answer some questions. These are simplified categories – greater detail can be found in the attached reports and provided on request.

Education	
High School or Less	n=30
Some College	n=53
College Graduate	n=54
Post-Graduate	n=41

Region	
Maricopa	n=99
Pima	n=44
Rural	n=35

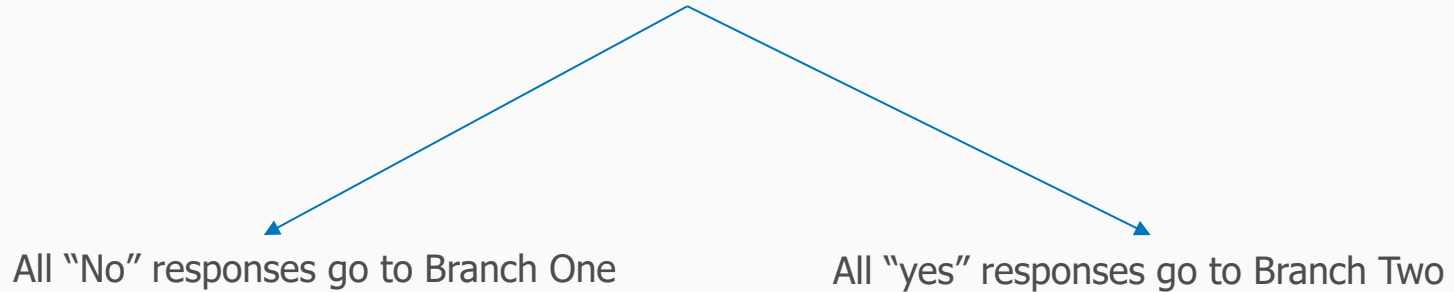
Ethnicity Combined	
White, non-Hispanic	n=97
Hispanic/Latino	n=34
Other	n=47

Gender	
Male	n=35
Female	n=133

Age	
18-34	n=22
35-44	n=44
45-54	n=38
55-64	n=43
65+	n=31

Meeting the Challenge – A Survey Structure that Serves Everyone

- Ask qualified respondents about their connection with the community: learn whether they're a parent, caregiver, I/DD professional, someone with I/DD, etc.
- Ask if they had experience with behavioral health crisis services



The branches include different questions, tailored to the experiences of each group

**BRANCH ONE:
Those Who Have NOT Used
Behavioral Health Services**

Demographics of Branch One

Some demographics may not add up to the overall sample size, as respondents were allowed to refuse to answer some questions. These are simplified categories – greater detail can be found in the attached reports and provided on request.

Education	
High School or Less	n=15
Some College	n=28
College Graduate	n=34
Post-Graduate	n=27

Region	
Maricopa	n=60
Pima	n=23
Rural	n=21

Ethnicity Combined	
White, non-Hispanic	n=59
Hispanic/Latino	n=23
Other	n=19

Age	
18-34	n=13
35-44	n=28
45-54	n=20
55-64	n=23
65+	n=20

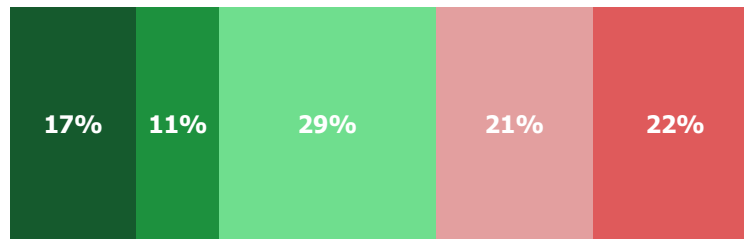
Gender	
Male	n=20
Female	n=82

Those who haven't used behavioral health services often don't understand how to use those services

- Key groups where a large percentage "barely" understood or did not understand "at all"
 - Black or African-American: 62%
 - HHI >\$100k: 61%
 - Caregivers: 50%
 - Ages 65+: 50%
- **Insight: some populations who need this understanding most don't have it.**

Do you understand how to get behavioral crisis services?

- 1 - Strongly understand
- 2 - Mostly understand
- 3 - Somewhat understand
- 4 - Barely understand
- 5 - Don't understand at all



Q) Do you understand how to get behavioral health crisis services? Answer on a scale from 1 to 5, with 1 indicating you strongly understand and 5 indicating you do not understand at all. (Total Respondents N=104).

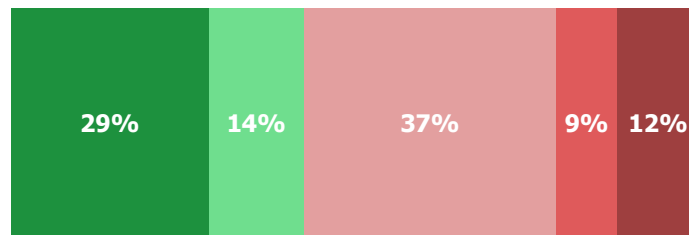
† Note: Some numbers (on the chart or elsewhere) may not appear to be totaled correctly. This is due to rounding.

But most are worried that they will need to use behavioral crisis services in the future

- Groups who are most worried (options 3-5)
 - Postgrads: 74%
 - HHI >\$100k: 73%
 - I/DD professionals: 71%
- **INSIGHT:** the groups who feel the most worry are NOT the groups with the lowest understanding of the system. **The people who worry the most are well-resourced – need to put in extra effort to reach other groups.**

Level of Worry for the Need for Behavioral Health Crisis Services in the Future

- 1 - Not worried
- 2 - A little worried
- 3 - Somewhat worried
- 4 - Quite worried
- 5 - Very worried

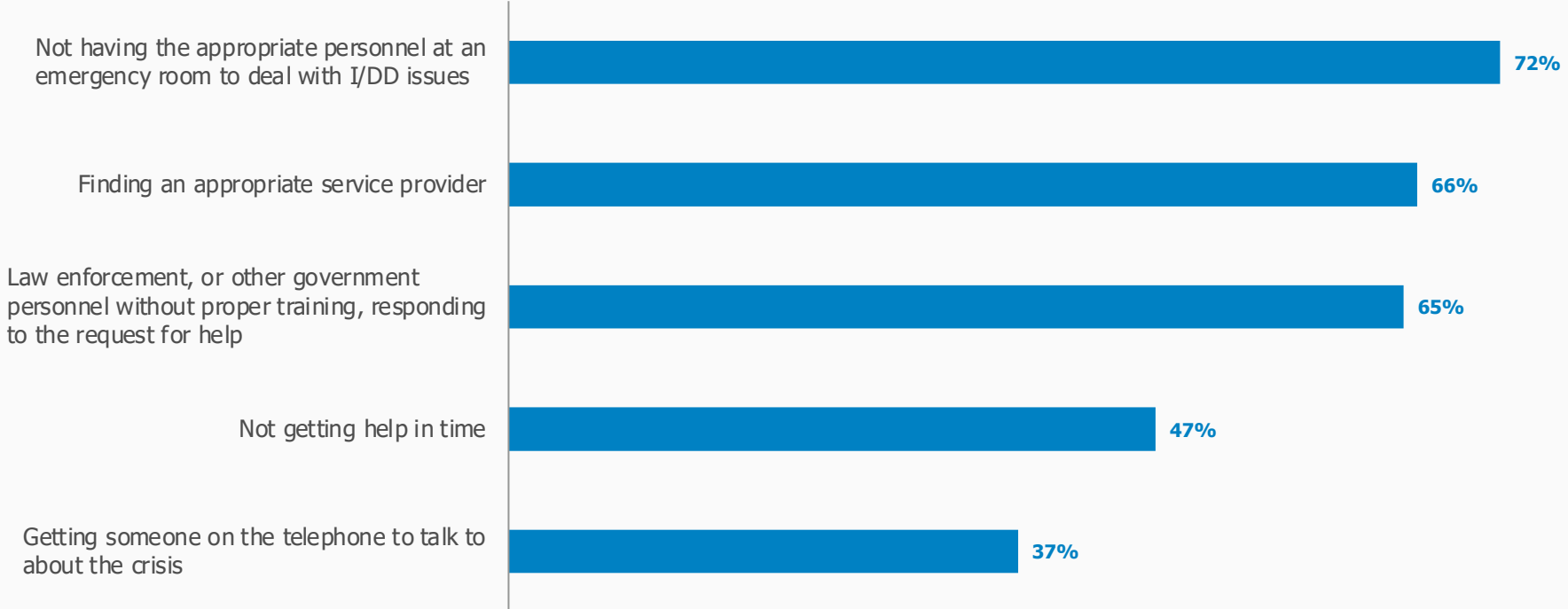


Q) Do you worry you or the person you care for may need to get behavioral health crisis services in the future? Answer on a scale from 1 to 5, with 1 indicating no worry and 5 indicating that you're very worried. (Total Respondents N=104).

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And many worry that, if a behavioral crisis were to happen, they'd encounter medical professionals or first responders with insufficient training

Top Five Perceived Obstacles



Q) If you were faced with a behavioral health crisis, what obstacles to using the behavioral health crisis services do you think you would encounter? Please select all that apply. (Total Respondents N=104).

† Note: Some numbers (on the chart or elsewhere) may not appear to be totaled correctly. This is due to rounding.

The worry is deep. Early in the survey – before we mentioned first responders without I/DD training – respondents brought up the idea.

The third question of Branch One, and the first free response question, reads: What would you do first in the case of a behavioral health crisis? Example: if the person you care for was a danger to themselves or others.

Most respondents said something like “call 911” or “handle it myself.” But others, without our prompting, brought up worries about first responders and medical personnel.

“Do not call police ever”

I/DD parent/guardian, Maricopa County, High school graduate

I/DD parent/guardian, suburban woman, HHI <\$50k

“Try to handle it myself. The hospital is a disaster for this population”

“We would not allow a behavioral health team to handle the crisis as they only treat I/DD cases as a psychiatric case and we wind up being mistreated.”

Woman with I/DD, age 18-34

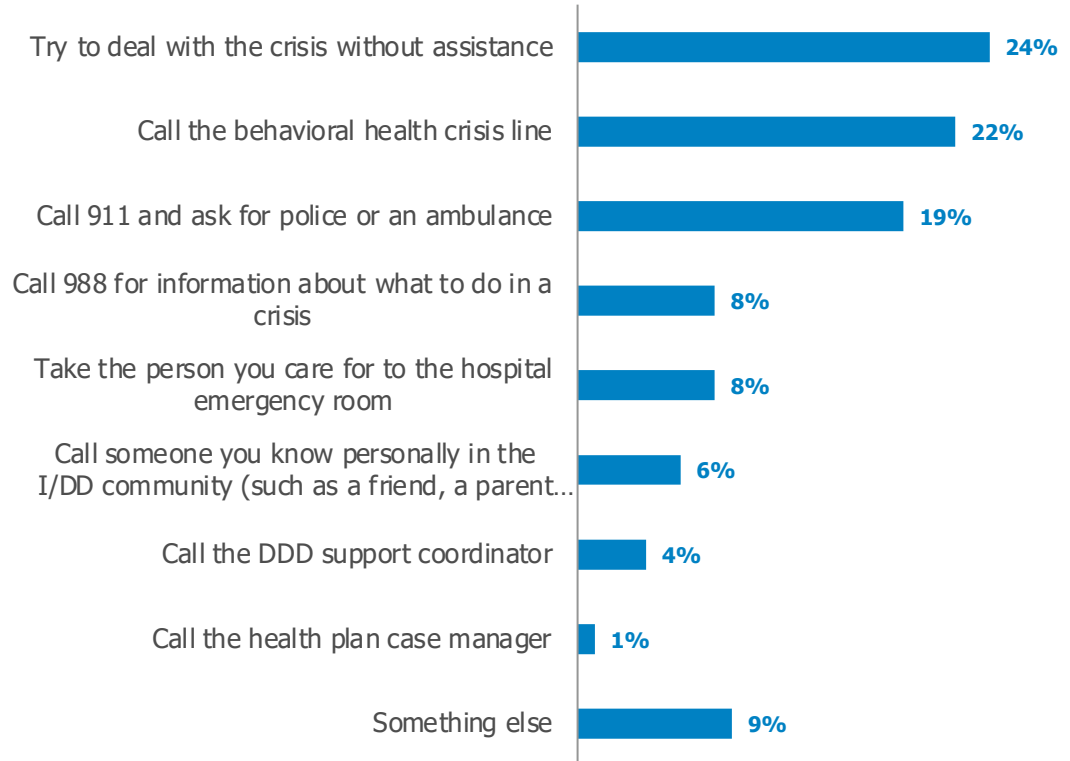


Q) What would you do first in the case of a behavioral health crisis? Example: if the person you care for was a danger to themselves or others.
† Note: Some numbers (on the chart or elsewhere) may not appear to be totaled correctly. This is due to rounding.

Many respondents would call 911, the crisis line or try to handle the situation themselves

- We also asked a version of this question with open-ended responses. Same overall finding: many would dial 911, dial 988 and handle it myself were common responses (see crosstab documents for more)
- Highest group for “try to deal with the crisis without assistance” – those with a high school diploma or less (40%)

In the event of a behavioral health crisis, which of these would you do first?

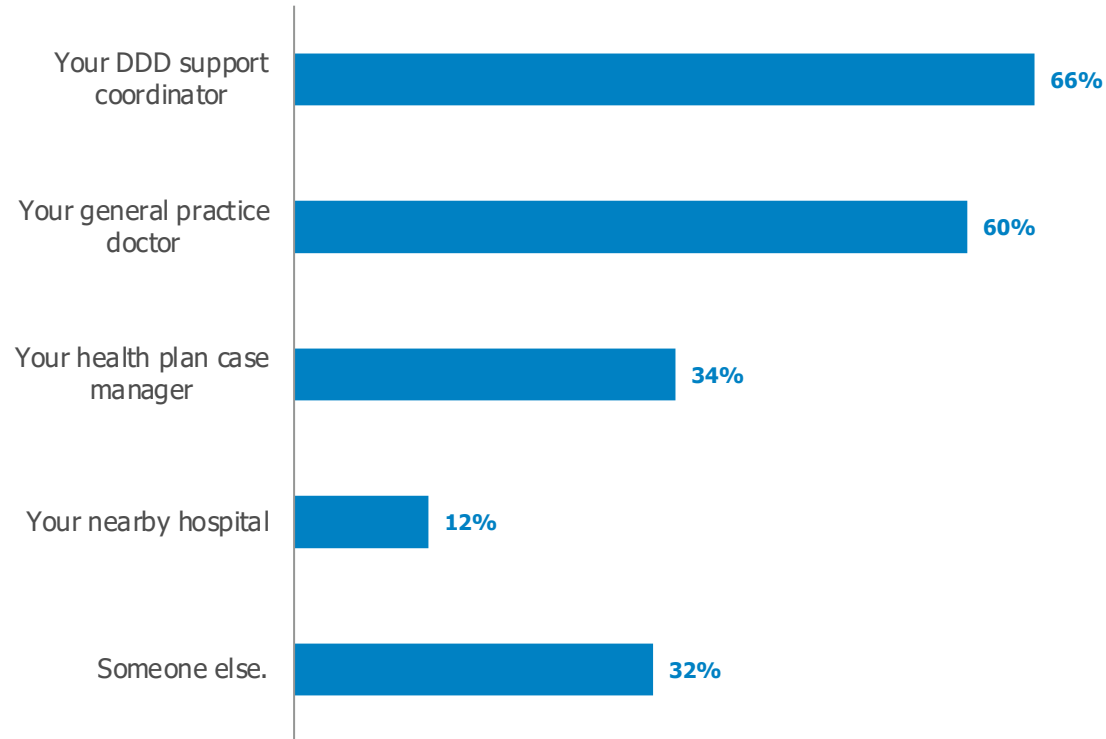


Q) In the event of a behavioral health crisis, which of these would you do first? (Total Respondents N=104).

† Note: Some numbers (on the chart or elsewhere) may not appear to be totaled correctly. This is due to rounding.

And, although two-thirds say that behavioral health issues should be addressed with a DDD support coordinator...

Who do you think you should talk to about behavioral health issues?



Q) Who do you think you should talk to about behavioral health issues? Please select all that apply. (Total Respondents N=104).

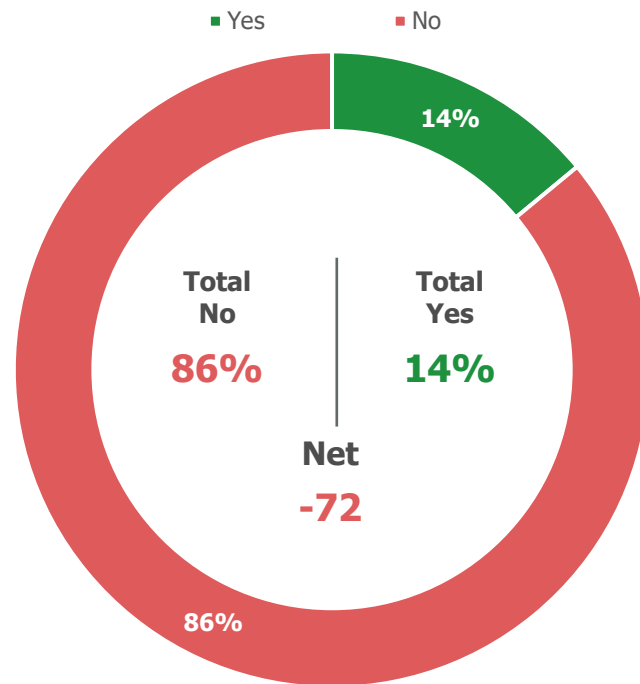
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Many haven't talked to their DDD support coordinator about what to do in a behavioral health crisis. Talking to them might help.

- DDD support coordinators are seen by many as a key help in the event of a behavioral health crisis.
- But many respondents haven't spoken to their DDD coordinator about what to do in a crisis situation.
- **FOLLOW-UP: Among those who said they HAD spoken with their DDD support coordinator, 67% were satisfied with the information.**



Have you ever talked to your DDD support coordinator about what to do in a behavioral health crisis?



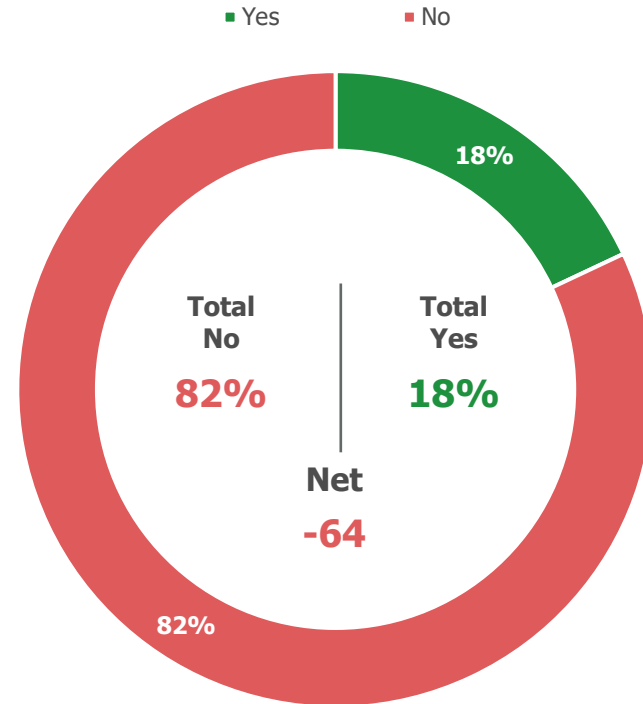
Q) Have you ever talked to your DDD support coordinator about what to do in a behavioral health crisis? Please select all that apply. (Total Respondents N=104).

† Note: Some numbers (on the chart or elsewhere) may not appear to be totaled correctly. This is due to rounding.

Respondents in this branch do not have a crisis plan

- This branch – those who had not interacted with behavioral health crisis services – often said they would attempt to handle situations by themselves.
- Respondents in this branch also worry that law enforcement or health professionals won't be trained to help individuals with I/DD.
- Some members of this group might be in danger of isolation in a crisis – handling a tough situation in the moment without using all available services.

Do you have a crisis care plan?



Q) Do you have a crisis care plan? Please select all that apply. (Total Respondents N=104).

† Note: Some numbers (on the chart or elsewhere) may not appear to be totaled correctly. This is due to rounding.



KEY TAKEAWAYS

- Those who have NOT used behavioral health services are unsure about first responders – specifically worried that they won't have the right training for the I/DD population.
- Calling 911 or the crisis line – or handling the situation themselves – is a preferred method of handling behavioral health crises.

- Respondents in this branch believe they should talk to the DDD support coordinator about what to do in a crisis – but many haven't.
- Those who HAVE had this conversation report learning and positive experiences.

**BRANCH TWO:
Those Who HAVE Used
Behavioral Health
Services**

Demographics of Branch Two

Education	
High School or Less	n=15
Some College	n=25
College Graduate	n=20
Post-Graduate	n=14

Region	
Maricopa	n=39
Pima	n=21
Rural	n=14

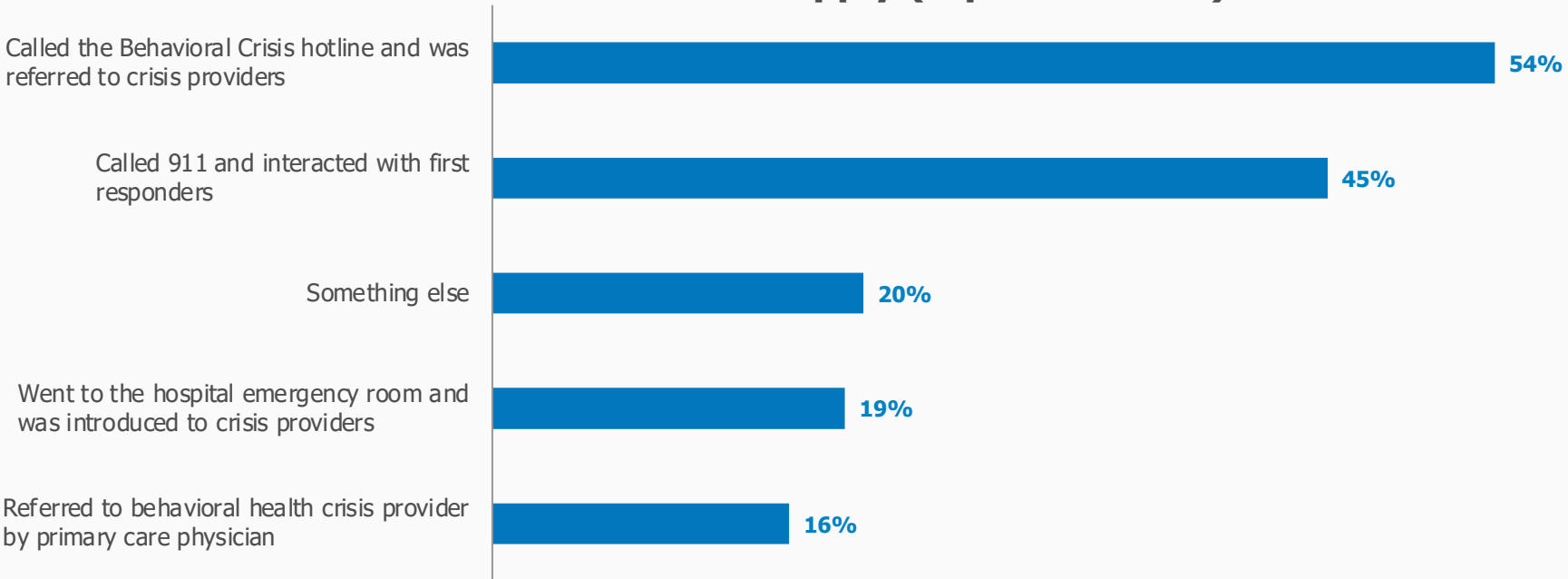
Ethnicity Combined	
White, non-Hispanic	n=38
Hispanic/Latino	n=11
Other	n=25

Gender	
Male	n=15
Female	n=51

Age	
18-34	n=9
35-44	n=16
45-54	n=18
55-64	n=20
65+	n=11

How people came into contact with behavioral crisis services: By calling 911 or the crisis line

How did you use the behavioral health crisis services? Please select all that apply (top five shown)



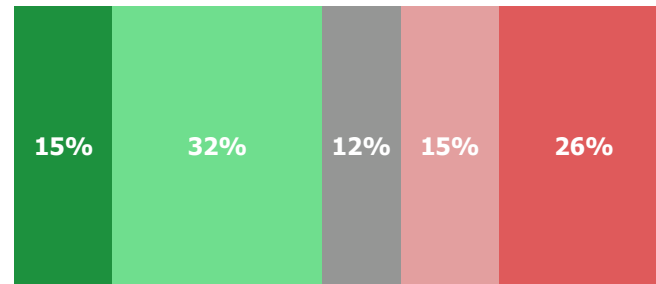
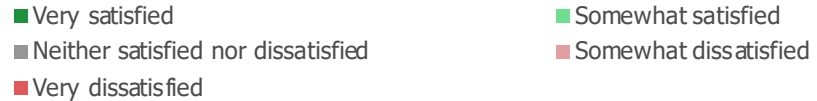
Q) How did you use the behavioral health crisis services? Please select all that apply. (Total Respondents N=74).
† Note: Some numbers (on the chart or elsewhere) may not appear to be totaled correctly. This is due to rounding.

The verdict was split on behavioral crisis services – some were satisfied, some weren't

Groups with the highest levels of dissatisfaction:

- Other gender / declined to answer: 62%
- Transgender or declined to say: 60%
- Black or African-American: 60%

Behavioral Health Service Satisfaction



Q) How satisfied were you with the behavioral health crisis services you received? (Total Respondents N=74).

† Note: Some numbers (on the chart or elsewhere) may not appear to be totaled correctly. This is due to rounding.

What worked well? What didn't? A unique question design.

- **If people said they were satisfied with the experience, they were FIRST presented with an open-ended question about what went well for them.** Then they saw an open-ended question about what did not work well.
- **The reverse was true for those who were dissatisfied.** They were asked to talk about what went poorly first, then what went well.
- **We used slightly different question wording for each group** Example: “You indicated that you were dissatisfied with the behavioral health crisis services you received. Please tell us about the services that did NOT work well for you” for those who were dissatisfied vs. “What did not work for you?” for those who were satisfied overall.
- **The goal: Get all respondents to talk about what went well AND what went poorly.**

Respondents in Their Own Words: What Went Well

"Thankfully one of our previous case managers was on-call and was who we talked to. Being familiar was a huge asset to getting behavior backed down. But it was just by chance that this happened this way."

*Caregiver and parent/guardian,
Pima County*

*Male, age 35-44, I/DD
parent/guardian*

"Hmmm, the occasional time when we were blessed to find a doctor who had enough understanding and experience to make good choices on how to help."

"Specifically assigned crisis worker that we had already established rapport with and my child knew"

*Suburban, HHI \$50-100k,
Caregiver and parent/guardian*

Also mentioned: CRC, crisis workers, medications, the crisis hotline, DDD, Banner ER, some police officers, the mobile crisis team, Mind 24/7, among others. Family getting a break from challenges at home, and individual responders or staffers who did a good job.

Key theme: relationships with care providers is huge.

Nothing.



Q) What behavioral health crisis services worked best for you? OR What behavioral health crisis services, if any, worked for you?
† Note: Some numbers (on the chart or elsewhere) may not appear to be totaled correctly. This is due to rounding.

Respondents in Their Own Words: What Went Well

Plurality of responses were simply “None” or “Nothing” – people who could not think of a positive aspect of their experience.

EXAMPLES:

“None. Poor feedback, poor communications, discharge plans often established without guardian involvement.”

I/DD professional, male, rural

*Hispanic, I/DD parent/guardian,
age 55-64*

“N/A. None were completely effective”

“It is rare for BH crisis system to work well for I/DD members”

*I/DD professional, Maricopa County,
Woman*

Respondents in Their Own Words: What Did NOT Go Well?

"It took hours for them to arrive. While at the CRC it was a quick evaluation and he was released. Nothing was done. Although he was having thoughts of harming someone else."

Hispanic, Pima County, I/DD parent/guardian

Male, 18-34, Black/African-American

"My son is non-verbal with severe autism he was having a very bad crisis to where he had to go to CRC they said they couldn't do anything for a child with autism made me feel helpless and like they didn't care at all"

"When it is determined an individual is I/DD they resist providing services, stating the condition I/DD not psychiatric. Often discharge patients who are not stable, inadequate psychiatric assessments & evaluations, overuse of telemed."

Male, rural, I/DD professional

Male, caregiver, Maricopa County

"Defining what is stable or not stable. Different opinions of behavioral health teams."

Respondents in Their Own Words: What Did NOT Go Well

"Crisis is nowhere near designed for DDD members. There are very limited crisis services that are appropriate for adult DDD members who might need a higher level of care"

*I/DD
parent/guardian,
female, age 45-54*

*I/DD professional,
Pima County*

"Finding a level I or II placement for further treatment and assessments that will take the member's health insurance with a DDD diagnoses or a violent diagnoses"

"I have a member that express suicidal ideation, When crisis showed up the member refuses to talk to them. Each time he makes these statements, I call crisis and they tell me that because he will not talk to us they will not show up."

*Male, I/DD professional, age
55-64*

*I/DD professional and
parent/guardian,
Maricopa County*

"It's a hit or miss system depending on who you get and what mood they are in. Feels like the training and level of care is not consistent."

"They did not arrive on some occasions, On other occasions the response time took hours. Once they arrive they are not able to help ASD/DD crisis situations."

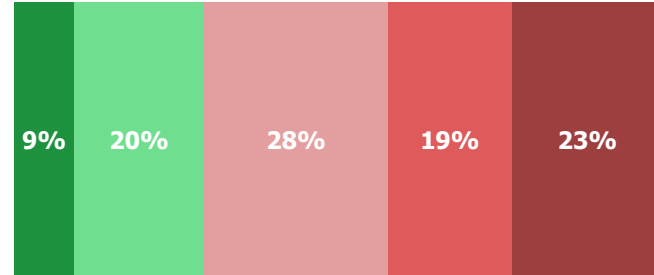
*Male, age 35-44,
postgraduate degree*

The overall verdict: Most people who received behavioral health services did NOT feel as if the crisis was resolved

- Groups with the highest level of dissatisfaction (3-5):
 - Transgender or prefer not to say: 100%
 - Other gender or decline to say: 100%
 - Hispanic/Latino: 91%
 - HHI >\$100k: 90%

Did Behavioral Health Services Help?

- 1 - Resolved to full satisfaction
- 2 - Resolved, but not to full satisfaction
- 3 - Only partially resolved
- 4 - Barely resolved
- 5 - Not at all resolved

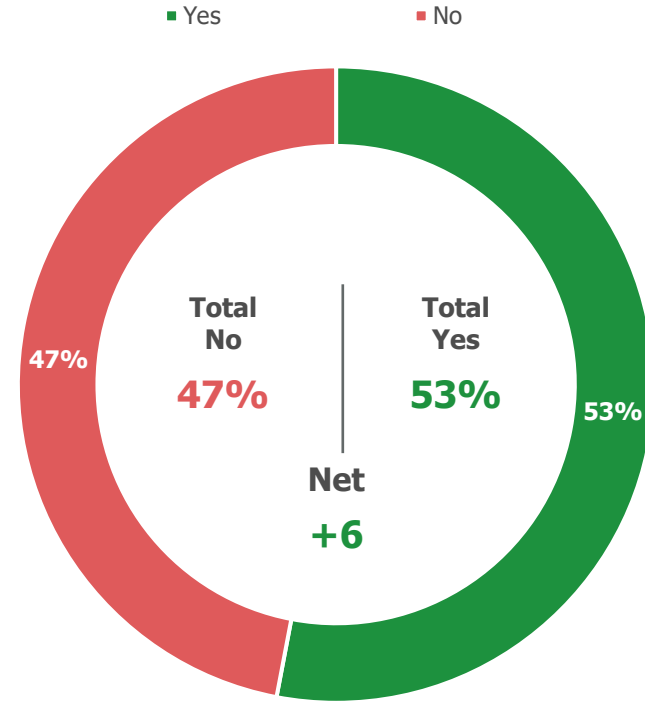


Q) Did the behavioral health crisis services provided to you resolve the crisis? Answer on a scale from 1 to 5, with 1 being resolved to full satisfaction and 5 being not resolved at all. (Total Respondents N=74).

† Note: Some numbers (on the chart or elsewhere) may not appear to be totaled correctly. This is due to rounding.

A significant chunk of respondents – roughly half within this branch – interacted with a mobile crisis team

Did a Mobile Crisis Team Provide Assistance?



Q) Did a mobile crisis team come to you when you asked for help? (Total Respondents N=74).

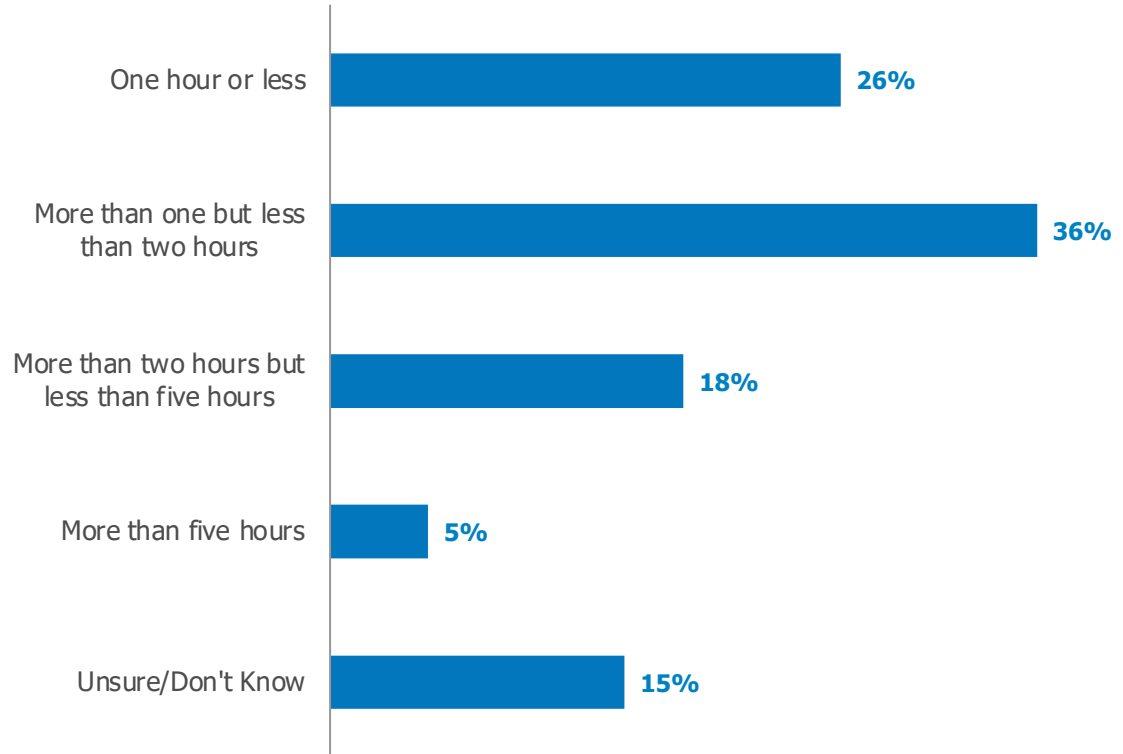
† Note: Some numbers (on the chart or elsewhere) may not appear to be totaled correctly. This is due to rounding.

The wait times were LONG.

But satisfaction was higher when a mobile team arrived.

- Among those who reported that a mobile crisis team came to them, 56% said they were satisfied with their experience.
- Among those who said a mobile team did NOT come when they asked for help, 37% reported being satisfied with their experience.

Length of Wait for Mobile Crisis Team

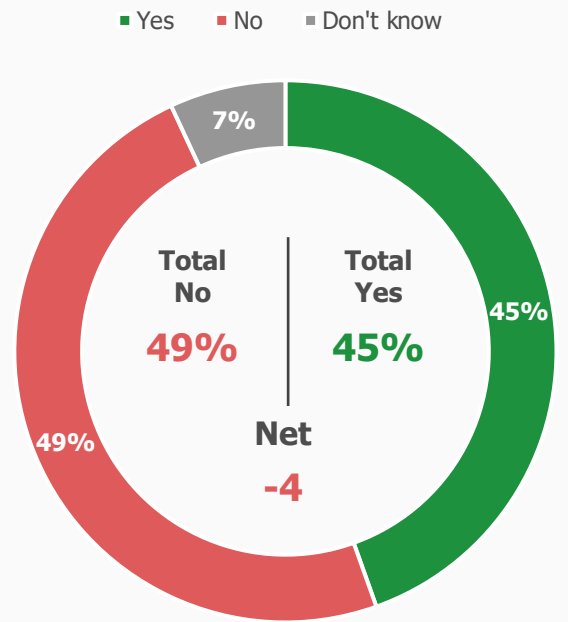


Q) How long did it take for the mobile crisis team to arrive? (Total Respondents N=39).

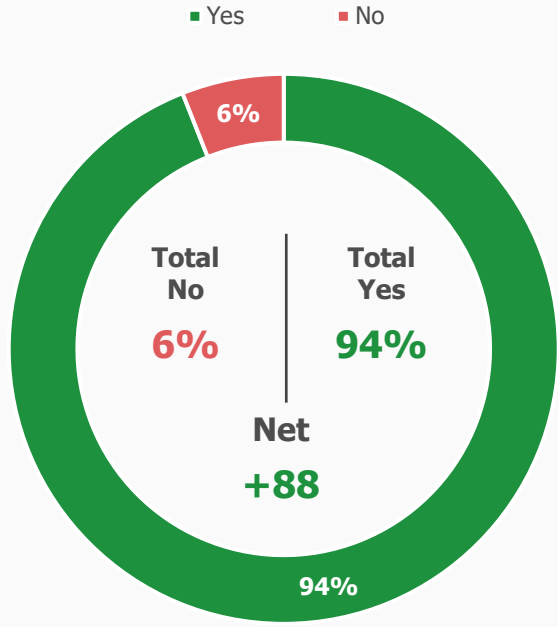
† Note: Some numbers (on the chart or elsewhere) may not appear to be totaled correctly. This is due to rounding.

Almost half of the respondents in this branch were admitted voluntarily to Behavioral Health Crisis Services. Most of them were admitted into inpatient services...

Behavioral Health Crisis Service Admission Rate



Did you receive inpatient treatment?

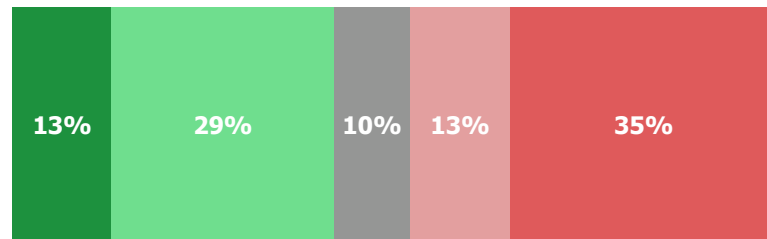
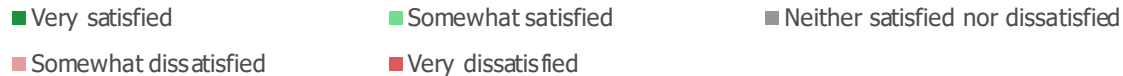


Q) Were you or someone you care for admitted voluntarily to Behavioral Health Crisis Services? (Total Respondents N=74). AND Did you or someone you care for receive inpatient treatment? (Total Respondents N=33).
† Note: Some numbers (on the chart or elsewhere) may not appear to be totaled correctly. This is due to rounding.

...But those who received inpatient treatment had mixed feelings about their experience

- Groups who were most dissatisfied:
 - College graduates: 67%
 - Pima County residents: 62%
 - White respondents: 62%

Inpatient Treatment Satisfaction

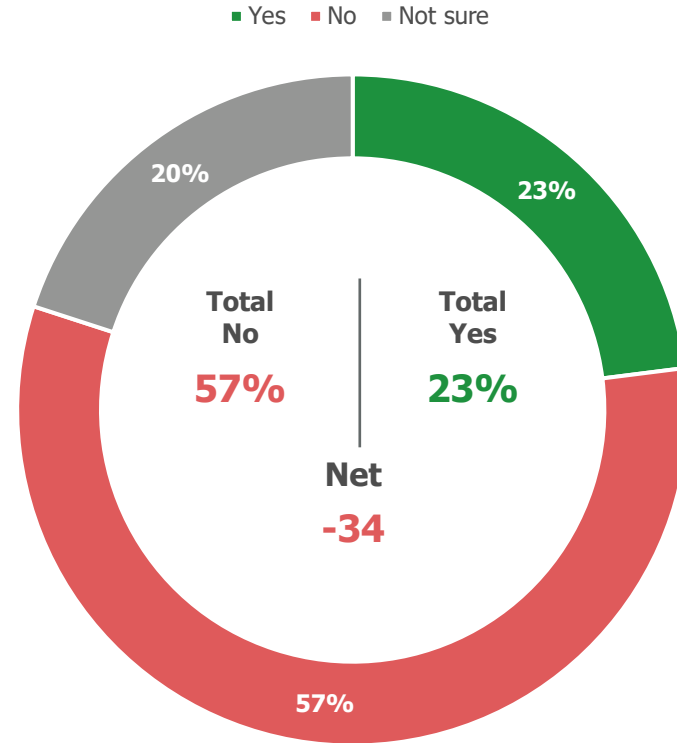


Q) How satisfied were you with the inpatient treatment? (Total Respondents N=31).

† Note: Some numbers (on the chart or elsewhere) may not appear to be totaled correctly. This is due to rounding.

Most respondents who interacted with behavioral crisis services did NOT receive instruction on how to prevent crises in the future

Preventative Methods Provided



Q) Did the behavioral health crisis provider teach you ways to avoid crises in the future? (Total Respondents N=74).

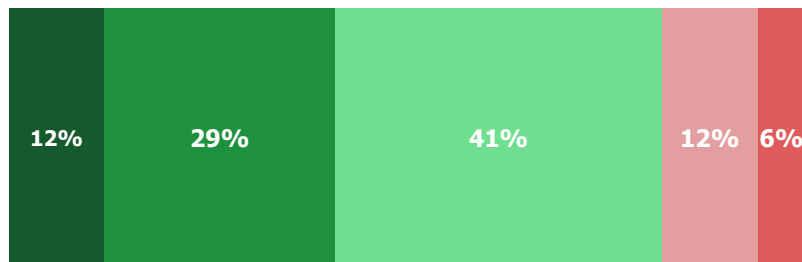
† Note: Some numbers (on the chart or elsewhere) may not appear to be totaled correctly. This is due to rounding.

BUT, among those who did, most found the advice to be helpful

Subgroups here are too small for meaningful demographic analysis.

Educational information has mostly worked to some degree

- 1 - Worked very well
- 2 - Worked well
- 3 - Worked somewhat well
- 4 - Did not work well
- 5 - Did not work at all

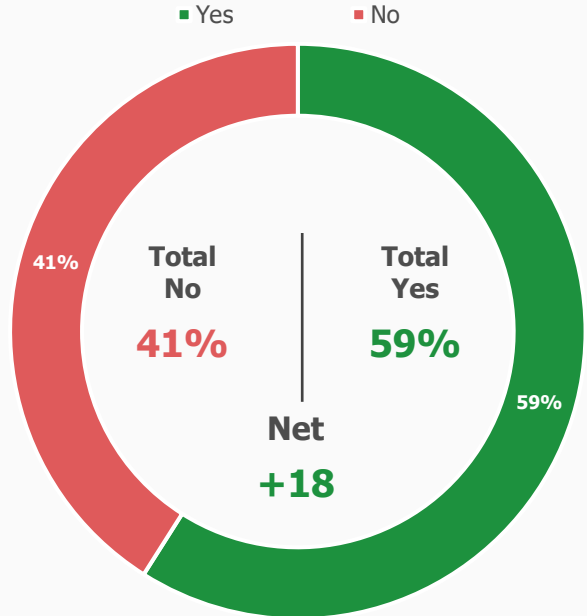


Q) Has that education helped you prevent a future behavioral health crisis? Answer on a scale from 1 to 5, with 1 indicating the interventions worked very well and 5 indicating that they did not work at all. (Total Respondents N=17).

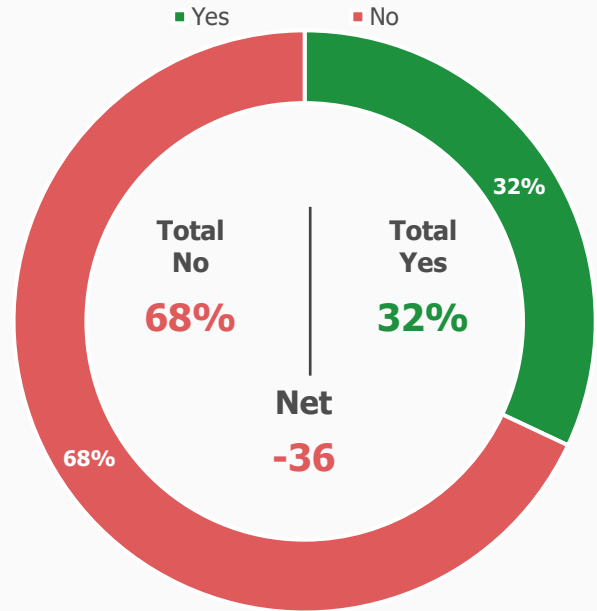
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And, just like those who had NOT received crisis services, respondents in this branch knew what medical power of attorney was... but most did not have one

Familiar with Mental Health Power of Attorney



Do You Have a Mental Health Power of Attorney?



Q) Are you familiar with a mental health power of attorney? (Total Respondents N=74) AND Do you have a mental health power of attorney for yourself or the person you care for? (Total Respondents N=44).
† Note: Some numbers (on the chart or elsewhere) may not appear to be totaled correctly. This is due to rounding.

Takeaways, Reviews, and Insights

There is some bad news, but some good news, too



Bad News: Among those who did not report experience with behavioral health crisis services, many were worried that first responders or other personnel wouldn't have the right training to handle the situation.

- Roughly 7 in 10 worried that an emergency room would not have professionals with proper I/DD training. A similar number were worried that law enforcement would not have the proper knowledge to help in a behavioral health crisis.



Bad News: Among those who DID report experience with behavioral health crisis services, many did not have a positive experience.

- Only 29% said that their crisis situation was either fully resolved or “resolved, but not to full satisfaction.”
- The rest said their situation was “partially” or “not at all” or “barely” resolved.
- Those who reported experience with behavioral health crisis services were NOT happy with the experience.



Good News: People who learned preventative strategies from their behavioral crisis provider benefited from them.

- Only a small group said that a behavioral health crisis provider taught them how to avoid crises. But, within that group, 82% said the education worked “somewhat well” “well” or “very well” in preventing a future crisis.
- When behavioral crisis providers help people understand how to avoid future behavioral health crises, people see the benefits.



Good News: Talking to the DDD coordinator helps.

- Among those who had spoken with their DDD coordinator about preventing a crisis, most found the information helpful.
- DDD and behavioral health crisis providers CAN help prevent future behavioral health crises by teaching.



Conclusion

- Many members of the I/DD community haven't used behavioral health crisis services – and many are worried about what would happen if they did.
 - I/DD community members who HAVE experienced behavioral health services have significant frustrations
- Many I/DD community members think they should speak with DDD professionals.
 - Many who received instruction – during their behavioral health crisis experience or from DDD personnel – reported benefiting from that education.

Research Methodology

This survey was administered online, with English and Spanish options, to Arizonans who identified as part of the I/DD community (having an intellectual or developmental disability, having someone with I/DD in your family, caring for someone with I/DD). The survey was distributed to selected social media groups, email lists, and other digital forums. The survey was launched on December 18, 2023. Due to feedback from the I/DD community, the client requested that the questionnaire be revised and resent, acknowledging that the total response count might be lower and field time may be longer as a result. Interviews included in the final report were collected between December 20, 2023 and January 26, 2024.

Some demographics may not add up to the overall sample size, as respondents were allowed to refuse to answer some questions. These are simplified categories – greater detail can be found in the attached reports and provided on request.

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High School or Less	30
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College Graduate	54
Post-Graduate	41

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Ethnicity Combined	
White, non-Hispanic	97
Hispanic/Latino	34
Other	47

Age	
18-34	22
35-44	44
45-54	38
55-64	43
65+	31

Gender	
Male	35
Female	133



NOBLE

PREDICTIVE INSIGHTS

Thank You

PHOENIX

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