

# 2021 AUTISM CARE DEMONSTRATION SURVEY



Exceptional Families  
of the Military



One Community,  
One Voice



# MISSION STATEMENT

Exceptional Families of the Military's mission is to connect military families with Disabilities, Special Healthcare Needs, or additional educational needs from all branches of the service in order to navigate within the Exceptional Family Member Programs and identify areas of improvement that affect the families we represent. Using the data we collect while simultaneously assisting our families, we endeavor to create long-lasting systematic changes in the laws and regulations that affect EFMP families.

We are committed to advocating on behalf of military families with autistic dependents. We believe the changes limit access to ABA services and negatively impact the lives of families with autistic loved ones. The data from the Autism Care Demonstration 2021 Tricare Operation Manual changes survey are to show legislators, the Defense Health Agency, and military leadership how families are affected and to share their voices. #EFMvoice

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# ABOUT THIS SURVEY

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The Autism Care Demonstration (ACD) Survey was created in October of 2021 by the Exceptional Families of the Military (EFM). In May of 2021, the DHA began implementing changes to the ACD and EFM noticed rising concern from military families enrolled in the ACD. The purpose of the ACD Survey created and distributed by EFM (2021) is to show various leadership how these changes are negatively impacting military families and their Autistic loved ones.

\*\*All questions in this survey were created by EFM and are intended for the use of only EFM and its users. Use by any other organization must be given permission.



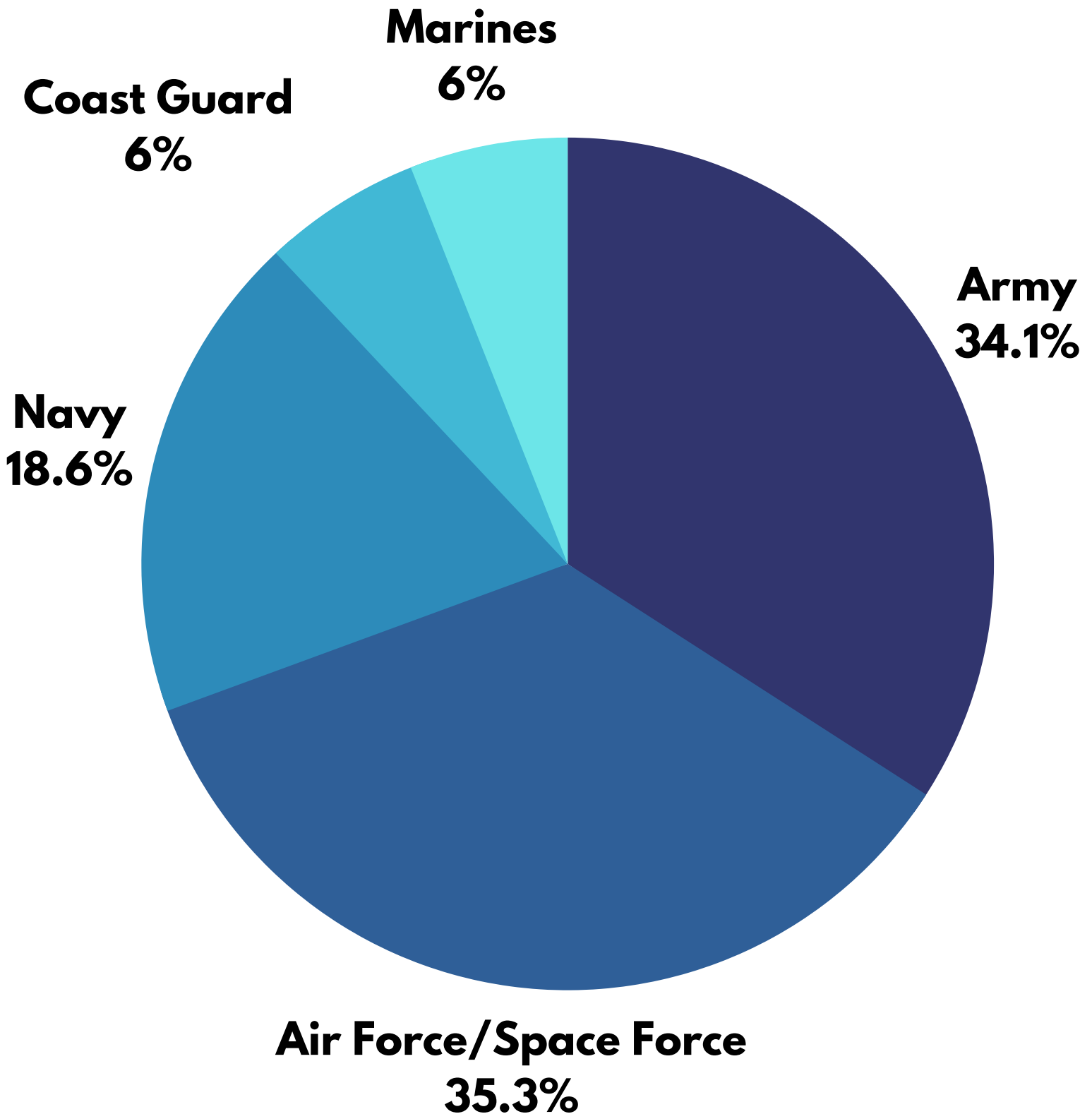
Exceptional Families of  
the Military



One Community,  
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# BRANCH OF SERVICE

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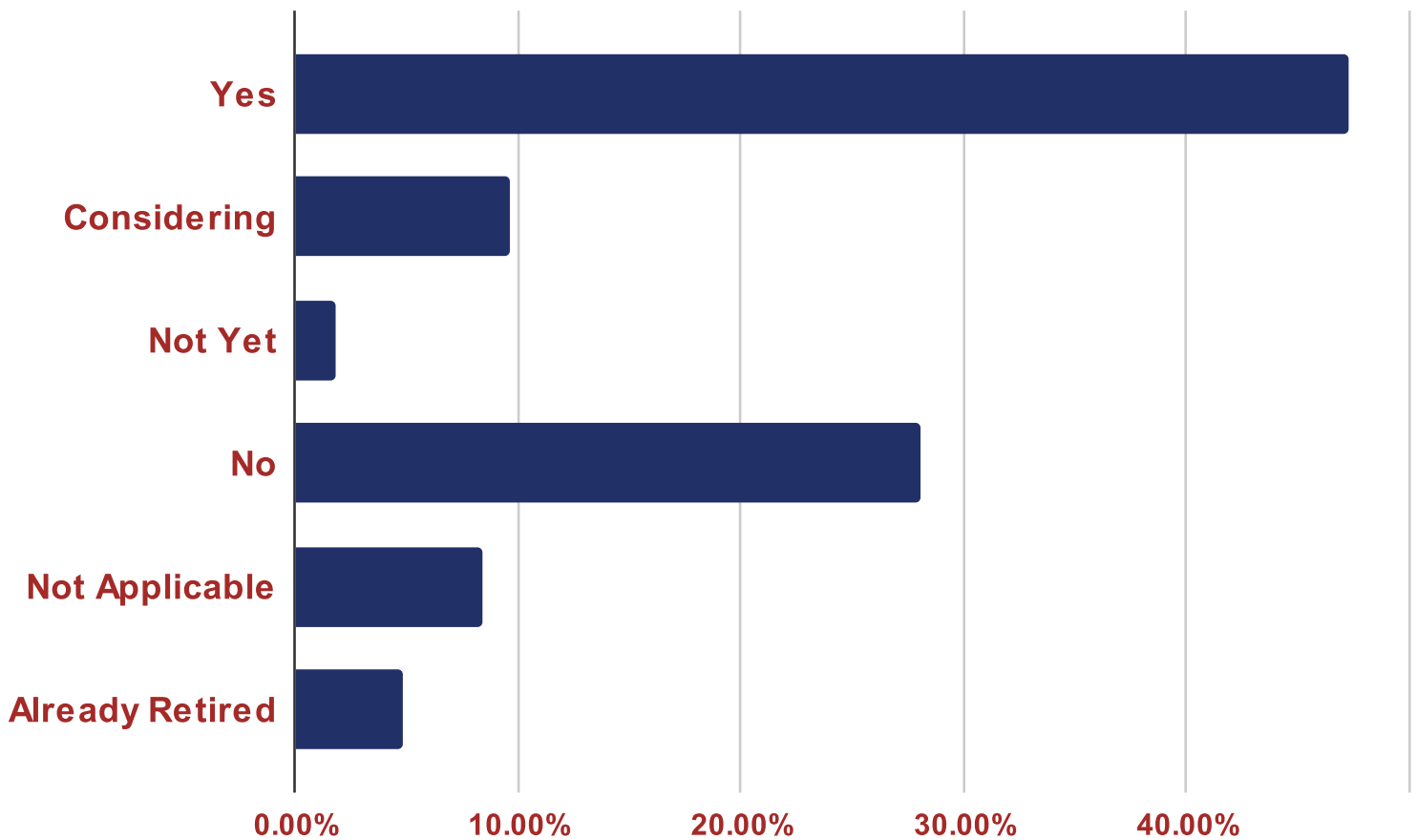


\*Due to the small number of Space Force respondents, Air Force and Space Force results are shown aggregate.



# QUESTION 1

Have the changes to the Autism Care Demonstration (ACD) program caused you to reevaluate your commitment to the military? (I.e. Have you made the choice to not reenlist or are you retiring because of these changes?)



*"Not only have the changes cemented my plans to not reenlist, but there have been many moments where I thought I was going to have to get out under the hardship program. We are dual military and the changes made it extremely difficult to find a center where we could get our [son] what he needs while still being able to fill our military obligations. The changes are incompatible with dual military life."*



# QUESTION 1 SUMMARY

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**Have the changes to the Autism Care Demonstration (ACD) program caused you to reevaluate your commitment to the military? (I.e. Have you made the choice to not reenlist or are you retiring because of these changes?)**

## Yes

- 47.3% (79 out of 167 respondents)
- 13 noted they would retire earlier than planned, ASAP, or not reenlist
- 6 noted they were retiring soon or were already retired

## Considering

- 9.6% (16 out of 167 respondents)
- 3 noted they would retire earlier than planned
- 2 noted they wanted the insurance

## Not Yet

- 1.8% (3 out of 167 respondents)

## No

- 28.1% (47 out of 167 respondents)
- 5 noted they were close to retirement or staying until they make retirement
- 2 noted they wanted the insurance

## NA

- 8.4% (14 out of 167 respondents)
- 5 left this question blank
- 1 noted they disagree with ABA and would like other treatment options available

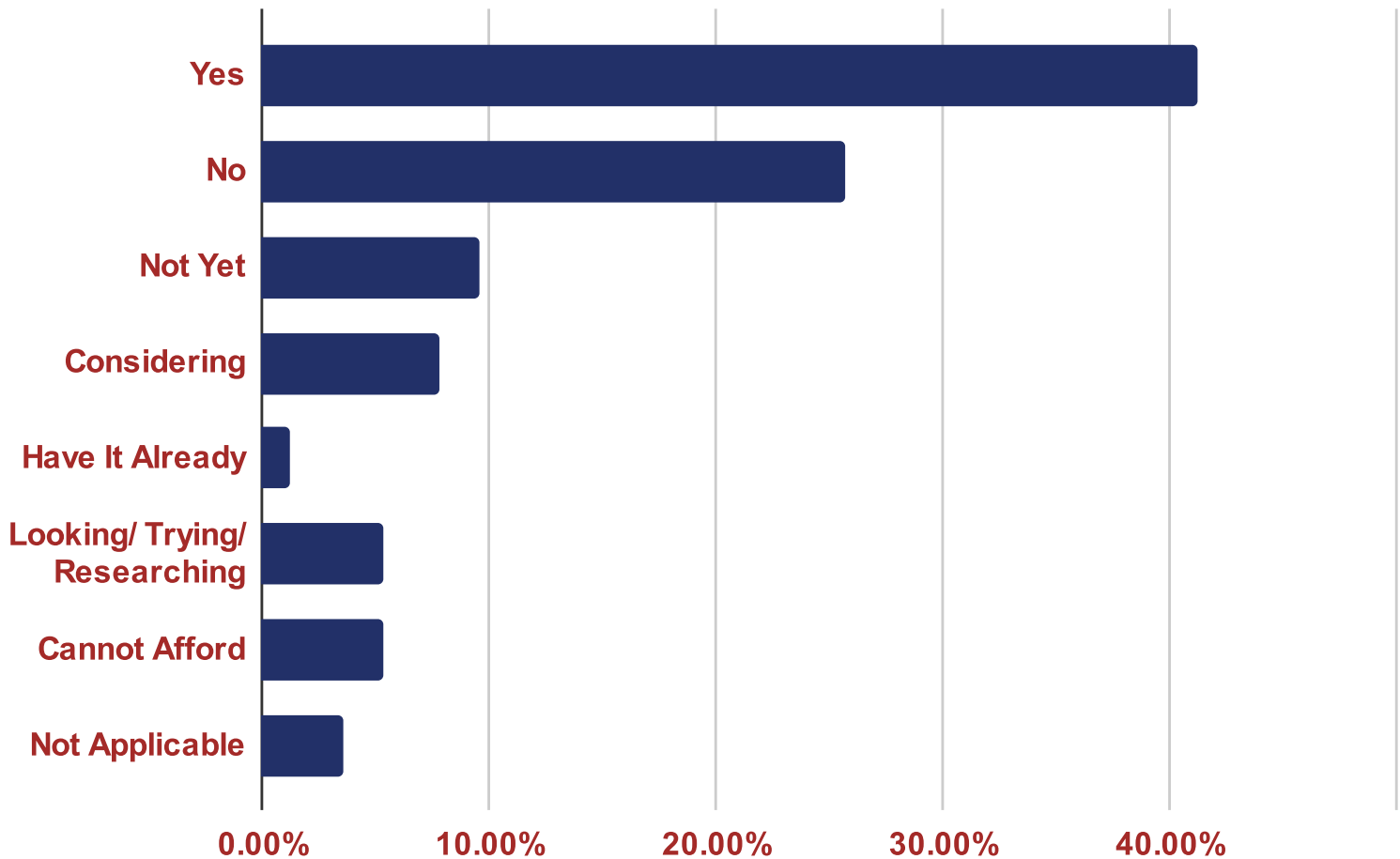
## Already Retired

- 4.8% (8 out of 167 respondents)
- 8 people noted they had already retired



# QUESTION 2

Have you sought secondary insurance to cover the services TRICARE will not cover?



*"No we can not afford it between the two of us we served over 30 years and can not provide care for our child."*

*"No. It's more cost effective to just leave"*



# QUESTION 2 SUMMARY

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## Have you sought secondary insurance to cover the services TRICARE will not cover?

### Yes

- 41.3% (69 out of 167 respondents)
- 2 noted trying to get Medicaid waivers, and wait lists years long
- 2 noted having/trying to get Medi-cal, but TRICARE limits what they can get
- 1 noted "Yes, I litigated for 2.5 years and my [child] was granted Medicaid under the [a] waiver. "

### No

- 25.7% (43 out of 167 respondents)
- 1 noted "It's more cost effective to just leave. "
- 1 noted "No but we pay significant amounts of money out of pocket. "

### Not Yet

- 9.6% (16 out of 167 respondents)

### Considering

- 7.8% (13 out of 167 respondents)
- 1 noted "If TRICARE accepts the referrals then we can't use medi-cal but I've thought about it. "

### Have it already

- 1.2% (2 out of 167 respondents)

### Looking/Trying/Researching

- 5.4% (9 out of 167 respondents)

### Cannot Afford

- 5.4% (9 out of 167 respondents)

### NA

- 3.6% (6 out of 167 respondents)
- 6 did not answer clearly or left the question blank



# QUESTION 3 SUMMARY

## How have the recent changes in the ACD affected your family?

There is no chart available for this question due to all answers being in comment form. Comments are broken out into the most commonly expressed concerns, where the main issues and feelings voiced by respondents are then summarized.

### Regression in behavior and skills

- Autistic individuals losing coping and social skills they worked so hard for
- Children being "ostracized" by peers
- Children have increasing problem behaviors at school

### Loss of ABA therapy in community settings and schools

- Children being moved out of inclusive environments into special classes/schools
- Parents have to choose between therapy and school
- School grades are dropping
- Students have increased stress and isolation from peers
- Families are trapped at home
- Individuals cannot tolerate dental visits or needed procedures, so go without
- Individuals cannot work on social skills without supported real world practice
- Autistic individuals and family members excluded from extracurricular activities

### Parent Stress Tests

- Parents must answer invasive and humiliating questions or child will lose services
- Parents upset they have to answer questions about their sex life for their child to access the services they need
- Quote "The parent stress index is innately flawed because it's essentially implying that our children are the sole cause of all of our stress. They are not all of the hoops we have to jump through in order to get our children the services [they]will need is an enormous cause of stress."

### Increased paperwork and overall stress

- Increased paperwork and approvals are causing service gaps
- Additional barriers to services are causing great stress and frustration
- Autistic individuals are experiencing greater anxiety without needed supports
- Military members concerned about stress level of autistic child without sufficient therapy to provide coping skills during frequent TDY's (Temporary duty Yonder)
- Changes causing great strain on dual military families
- Red tape makes some feel the stress is not worth the little therapy they get now

# QUESTION 3

## SUMMARY CONTINUED

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### How have the recent changes in the ACD affected your family?

#### Delays/Gaps in services/Reduced therapy hours

- Large gaps in service while finding providers who accept TRICARE
- Delays for TRICARE authorizations and referrals creating significant service gaps
- Hurdles for providers creating large gaps in services
- Assessment delays creating gaps in services
- Large decrease in service hours for families

#### ABA Providers dropping TRICARE

- Providers not getting reimbursed timely by TRICARE are considering dropping services for military families
- Providers are choosing not to take on new TRICARE patients
- Scarce providers willing to accept TRICARE means long wait lists/service gaps
- Families lose familiar Registered Behavior Technicians (RBT'S) because the RBT cannot wait indefinitely for TRICARE hour authorizations
- Quote "Our provider is no longer accepting tricare so I have taken 2 part time jobs to pay for secondary insurance in order to ensure my children (3 with ASD) continue to get exceptional services. "

#### Miscellaneous Comments

- Denial of toileting goals means some children are losing access to school options
- Some parents would like alternative options to ABA available
- Increased out of pocket expenses and financial strain
- Causing difficulty with Permanent Change of Station (PCS/military move)
- Quote "The more therapies our kiddos receive, the easier life is for them and the easier home life is for the servicemen. "
- Quote "Reduces access to required care"
- Quote "Essential Goals and programs are no longer covered that are critical for my son's growth "

*"My son is not able to get the amount of therapy he needs to be successful which makes everything more stressful. My current assignment requires frequent TDYs which causes more behaviors in my son and he doesn't have the adequate amount of ABA therapy to teach him the skills to cope with the change."*



# QUESTION 4 SUMMARY

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**How have the recent changes in the ACD affected your child's ability to participate or engage in the community (including, but not limited to school)?**

There is no chart available for this question due to all answers being in comment form. Comments are broken out into the most commonly expressed concerns, where the main issues and feelings voiced by respondents are then summarized.

## Regression

- Quote "Our kids social skills have majorly regressed because we can't get help."
- Quote "He was not at a place where he can do things alone just yet, but now I don't know if he ever will because we have lost so much of his progress."
- Quote "Our son has regressed quite a bit with behaviors and has been in constant trouble at school when he was doing really well last year and was making progress."

## Loss of community therapy and socialization practice

- Practice at home is not the same as in public with stressors and triggers
- Increased stress for everyone
- Lack of inclusion
- Cannot learn how to tolerate the doctor's office, haircuts, and social settings such as birthday parties
- Isolation from COVID has made outings even more stressful
- Cannot have needed dental procedures because they cannot tolerate the setting
- Quote "He is sad scared and completely overwhelmed. This will hinder his abilities to appropriately socialize with his peers."
- Quote "Not having the ABA therapist able to help work through these situations means that my wife cannot take my son to the store because of behaviors that will inevitably come during the outing."

## Trapped at home for therapy/Secluded/Lost fun activities

- Cannot socialize with peers
- Quote "Not having ABA in school or at stores/outings makes us more secluded."
- Quote "We can't go anywhere. At all. It's all too much."
- Quote "We can no longer go out as a family if we don't have both parents to attend the outing. We can no longer work on goals that address behaviors when around unfamiliar people."
- Having to do all therapy after school means no time for extracurricular activities
- Quote "Puts my family as hostages in our home because we don't have the support and therapy in natural environments."

# QUESTION 4

## SUMMARY PAGE 2

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**How have the recent changes in the ACD affected your child's ability to participate or engage in the community (including, but not limited to school)?**

### **Loss of ABA services in schools**

- Some have to change schools or reduce school hours to accommodate therapy
- Children being moved out of inclusive classes and schools due to loss of support
- More families are having to homeschool due to loss of support
- Children are exhausted when they start ABA after school
- Quote "It has limited our ability to target any ABA goals because we primarily utilized ABA during school hours. It is hard for him to have a full school day and they go to receive ABA therapy because he is tired from the day"
- Quote "My son hasn't been able to engage with other children and refusing to participate in group work in school."
- Quote "Because there will be no ABA therapist to assist in a normal classroom he is forced in to a development class with only other children demonstrating development issues. He learns bad habits from them. He has no example to follow of age appropriate developed children in the normal classroom now."
- Quote "My children are behind in school and have increased social anxiety"

### **TRICARE Communication**

- Quote "These changes, depending on who you talk to within [TRICARE] you get a different answer.... Their definition of community and everyone else's is completely different. As for my family personally we're being denied over some thing that other families were approved for. To say this is frustrating as putting it lightly."

### **Providers Scarce/Lost Services**

- Families losing providers due to changes and testing requirements
- Quote "He no longer has an ABA provider because no one has after school availability and he cannot receive services during the school day like he used to. "
- Quote "[Changes] excluded and restrict my kids from services"
- Quote "Her BCBA quit and he's going to another company that doesn't except TRICARE."



# QUESTION 4

## SUMMARY PAGE 3

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**How have the recent changes in the ACD affected your child's ability to participate or engage in the community (including, but not limited to school)?**

### Safety Concerns

- Increased anxiety is leading to increased elopement (wanders/runs away)
- Quote "One of my kids is an escape artist and needs 1:1 for safety reasons. Now we can't get help to work on those safety skills and I'm afraid he's going to be in another dangerous situation as a result."
- Concerns about awareness of safety and running into parking lots
- Halloween is stressful causing [my] child to run at activities or from decor in stores
- Quote "Yes. Without the direct support of therapist during outings it makes it difficult to know what to do in this situation even after being trained."
- Quote "If my son at 10 has a meltdown at the grocery store and becomes aggressive without a therapist with us, we are at risk of others calling the police and my child is at a higher risk of getting hurt because untrained NONmedical personal [respond. Persons] who are trained and do this for a living are not allowed due to the increased exclusion of these services. Putting our family at risk for our son being arrested, hospitalized or worse."

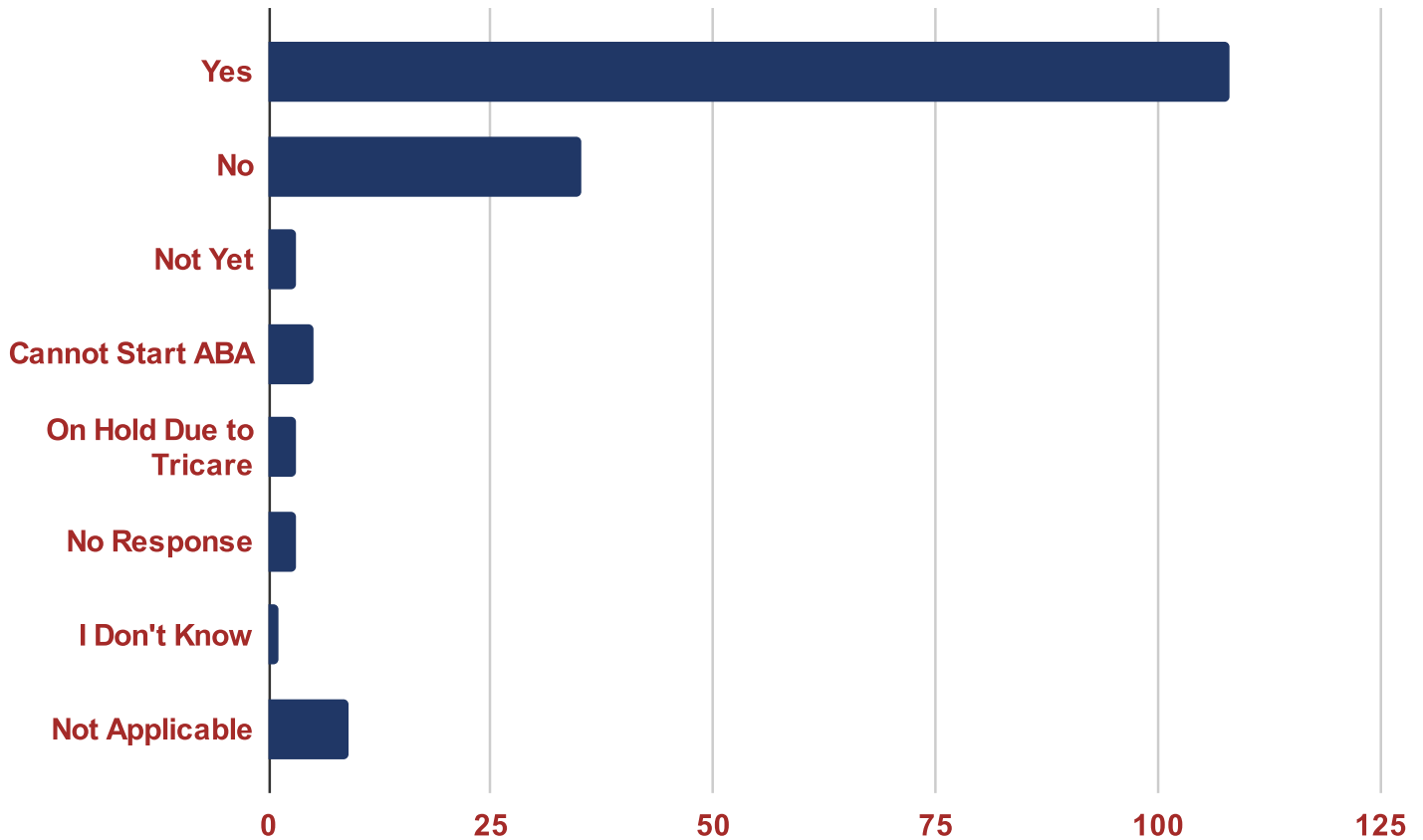
### Miscellaneous

- Creates difficulties during PCS (Permanent Change of Station /military move)
- Medical conditions and COVID causing issues too
- Respite provider shortage
- Families don't know how to get the care and therapy they need
- Twice exceptional students (gifted & autistic) are not having education needs met
- Quote "Yes. Unable to progress in basic life functions."
- Quote "We aren't able to utilize ABA for our child's identified deficits."
- Quote "She isn't able to be social. My daughter is 13 and has never had a friend."
- Quote "Our older son needs specific help with empathy, attending, and understanding age level things such as idioms. These are now considered too educational and not "autistic" enough. These things are important for him to be confident and participate adequately in the community. "

*"My child is not allowed in community settings with our company anymore. I have deployed and my wife is struggling to take my children out to community things because my daughters behavior and safety issues."*

# QUESTION 5

Have you had to decrease your child(ren's) hours of ABA against what is clinically recommended due to the changes of the community/school setting?



\*See page 15 for summary of hours family reported losing\*

*"Yes, he went from getting 30 hours a week of ABA (which he desperately needs) to 8 hours a week now that we are forced to do in home or center based. With 2 full time working parents, a parent who is gone sporadically a significant amount of time due to active military status and MOS, mom is forced to reduce hours at work to accommodate therapy schedules. Therapists not being allowed to support during normal community outings has made it difficult to accommodate and work through behaviors within the community. These are normal, life tasks with triggers that CANNOT be replicated in home or in center based therapy."*



# QUESTION 5 SUMMARY

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**Have you had to decrease your child(ren's) hours of ABA against what is clinically recommended due to the changes of the community/school setting?**

## **Yes**

- 64.7% (108 out of 167 respondents)

## **No**

- 21% (35 out of 167 respondents)

## **Not Yet**

- 1.8% (3 out of 167 respondents)

## **Cannot start ABA**

- 3% (5 out of 167 respondents)
- Still awaiting approvals or cannot get into ABA therapy (reasons not clear)

## **On Hold Due to TRICARE**

- 1.8% (3 out of 167 respondents)

## **No Response**

- 1.8% (3 out of 167 respondents)

## **I Don't Know**

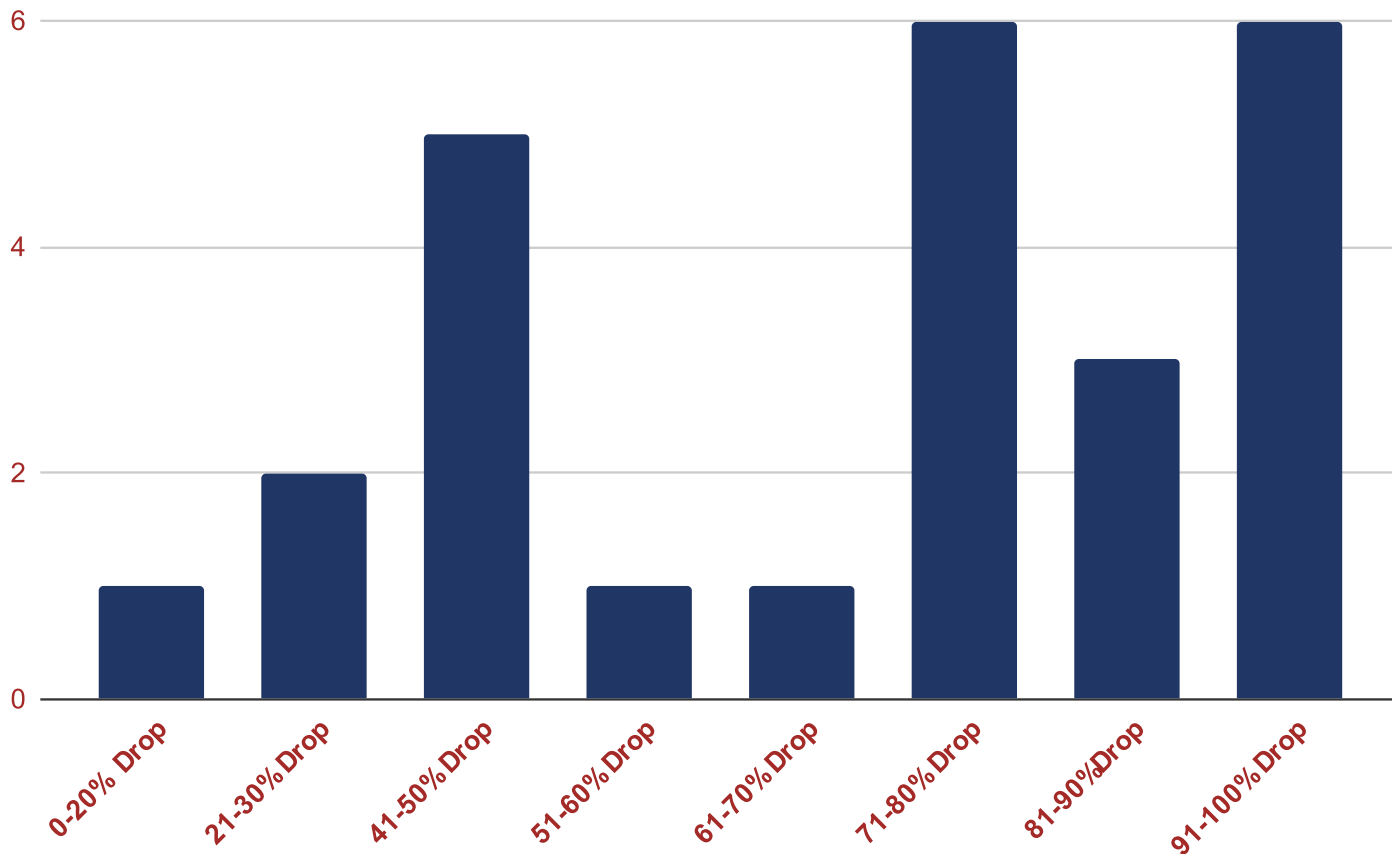
- 0.6% (1 out of 167 respondents)

## **NA**

- 5.4% (9 out of 167 respondents)
- Respondent did not answer clearly or left the question blank

# QUESTION 5 SUMMARY

Have you had to decrease your child(ren's) hours of ABA against what is clinically recommended due to the changes of the community/school setting?



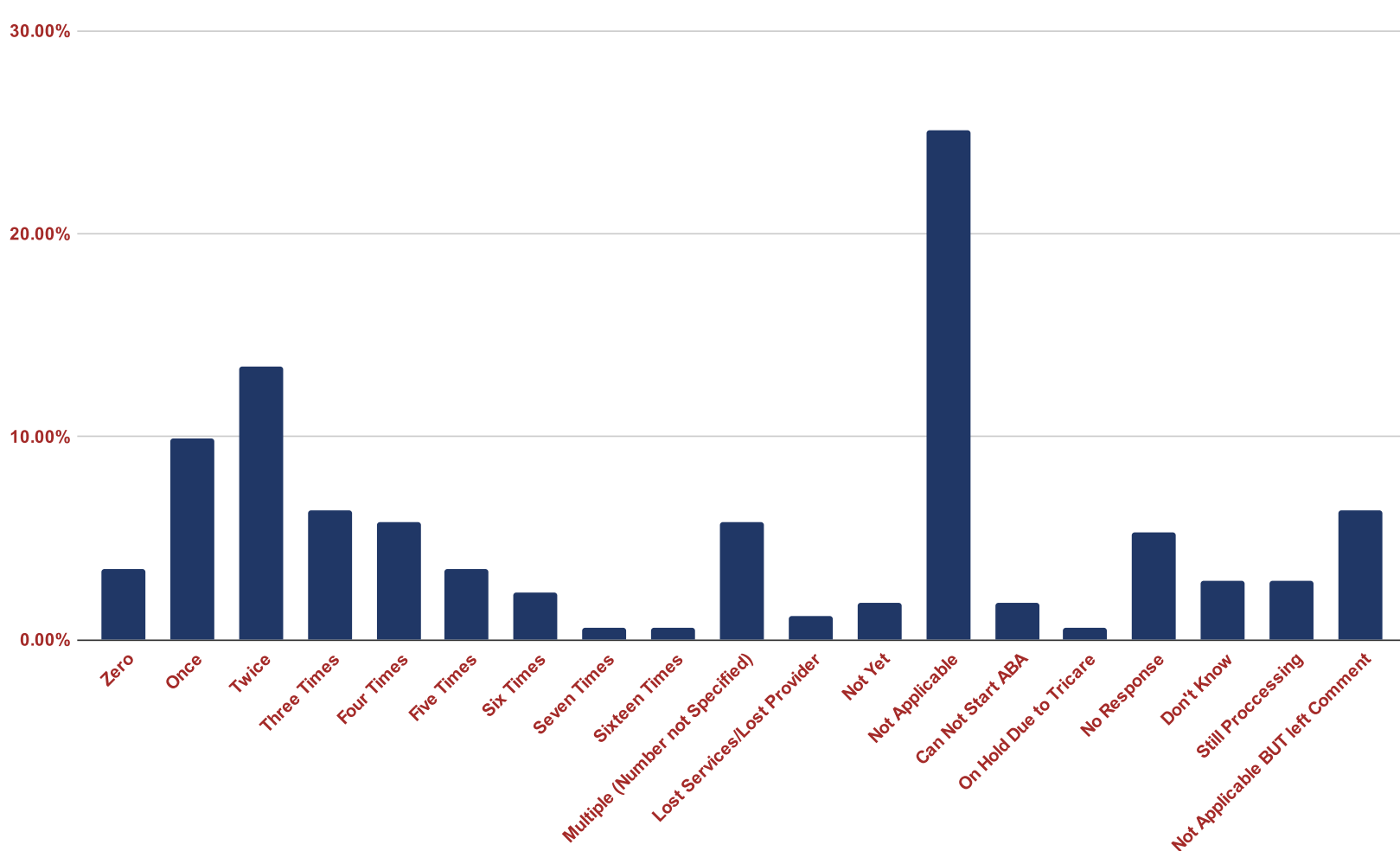
## % Decrease reported from Medically Recommended Therapy Hours

**Breakout:** 25 respondents provided statistics for the number of hours their child lost from their medically recommended therapy hours due to the changes. Hours started at 12-30hrs/wk before the decrease:

1 reported a 0-20% drop	1 reported a 61-70% drop
2 reported a 21-30% drop	6 reported a 71-80% drop
5 reported a 41-50% drop	3 reported an 81-90% drop
1 reported a 51-60% drop	6 reported a 91-100% drop

# QUESTION 6

How many times has/have your child(ren's) treatment plan for ABA been denied after the new TRICARE policies went into effect? (Please type N/A if your child's treatment plan has not been denied.)



*"We were denied several times and lost a months worth of services for one child and going on three weeks of services for another child."*



# QUESTION 6 SUMMARY

How many times has/have your child(ren's) treatment plan for ABA been denied after the new TRICARE policies went into effect? (Please type N/A if your child's treatment plan has not been denied.)

Number of Denials	Number of Respondents	Percent out of 171 Responses
0	6	3.5%
1	17	9.9%
2	23	13.5%
3	11	6.4%
4	10	5.8%
5	6	3.5%
6	4	2.3%
7	1	0.6%
16	1	0.6%

**Note:** Not all providers share information on the approval process with their clients so some families may not be aware of denials for their family member.

**\*\*** Some families gave a count for multiple children's denials. We included each child as a respondent in the tally, so this question has 171 responses instead of 167. **\*\***

## Multiple

- 5.8% (10 out of 171 respondents)
- Exact numbers were not given but multiple denials occurred
- Quote "We were denied several times and lost a months worth of services for one child and going on three weeks of services for another child."

## Lost Services or Lost Provider

- 1.2% (2 out of 171 respondents)
- Quote "It has not been denied, just services cut off entirely and due to this we lost the best ABA therapist we have ever met. We also have had a massive turn over in the ABA therapy place due to this."

## Not Yet

- 1.8% (3 out of 171 respondents)

# QUESTION 6

## SUMMARY CONTINUED

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**How many times has/have your child(ren's) treatment plan for ABA been denied after the new TRICARE policies went into effect? (Please type N/A if your child's treatment plan has not been denied.)**

### NA

- 25.1% (43 out of 171 respondents)
- Per instruction in the question wording, this includes answers for people whose plans have not been denied but may include people who chose to not respond to the question, as well as people who have not had to start the process yet.

### Cannot Start ABA

- 1.8% (3 out of 171 respondents)

### (Services) On Hold Due to TRICARE

- 0.6% (1 out of 171 respondents)

### No Response

- 5.3% (9 out of 171 respondents)

### I Don't Know

- 2.9% (5 out of 171 respondents)
- Providers may not have shared information on the approvals their clients

### Pending (Still Processing)

- 2.9% (5 out of 171 respondents)
- Process is ongoing
- Respondents report multiple denials and having to change multiple goals for their family member due to the ACD changes

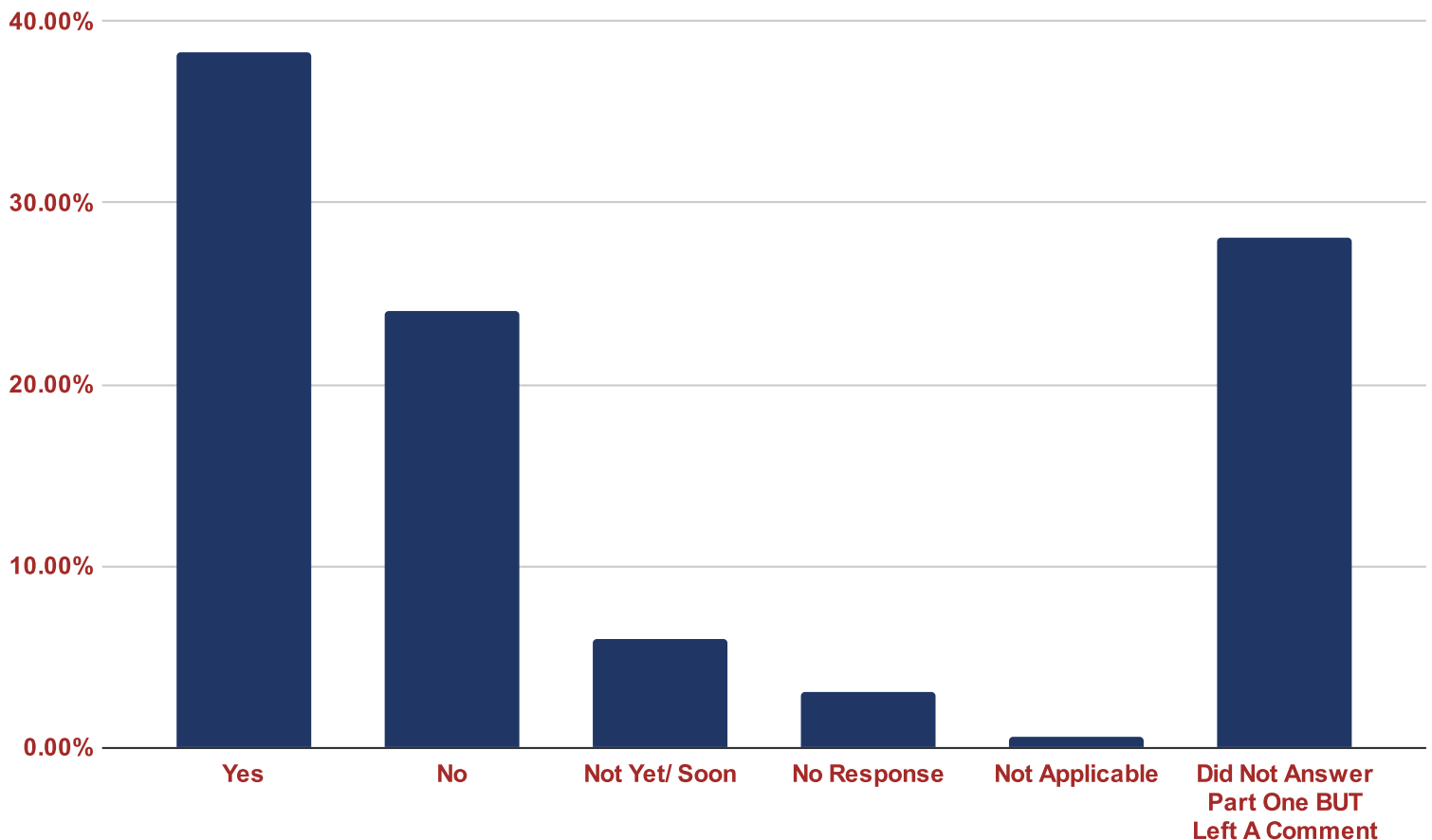
### NA with comment

- 6.4% (11 out of 171 respondents)
- Answers that did not provide a quantity but did include a comment
- Quote "N/A since we didn't renew with the changes and are on a break."
- Quote "NA...our center cannot even write a treatment plan because the goals they would have for him cannot be targeted under the current rules"



# QUESTION 7

Have you taken the Parent Stress Index (PSI) or the Stress Index for Parents of Adolescents (SIPA)? What are your thoughts on these parent stress assessments?



*“This assessment is invasive and is NO indication of how children are progressing. Many of the questions don’t take into account that we are married to deployed (or deployable) service members and the stressors associated with the military and not ASD.”*

\* There was very high participation in this question. Of the 162 people who input a response to this question, only 28 did not comment on the Parent Stress Test. 23 of those had not taken it. Only 5 people who answered yes gave no comments.



# QUESTION 7 SUMMARY

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**Have you taken the Parent Stress Index (PSI) or the Stress Index for Parents of Adolescents (SIPA)? What are your thoughts on these parent stress assessments?**

## **Yes**

- 38.3% (64 out of 167 respondents)

## **No**

- 24% (40 out of 167 respondents)

## **Not Yet**

- 6% (10 out of 167 respondents)

## **No Response**

- 3% (5 out of 167 respondents)
- question was left blank

## **NA**

- 0.6% (1 out of 167 respondents)
- response was "N/A"

## **Did not answer part 1 of the question but left a comment**

- 28.1% (47 out of 167 respondents)

**Note: Aside from five respondents who left this question blank, only 28 respondents did not comment on this question. 23 of those had not taken it. Only five people who answered yes gave no comments.**

# QUESTION 7 SUMMARY

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**Have you taken the Parent Stress Index (PSI) or the Stress Index for Parents of Adolescents (SIPA)? What are your thoughts on these parent stress assessments?**

## Questions asked by survey respondents

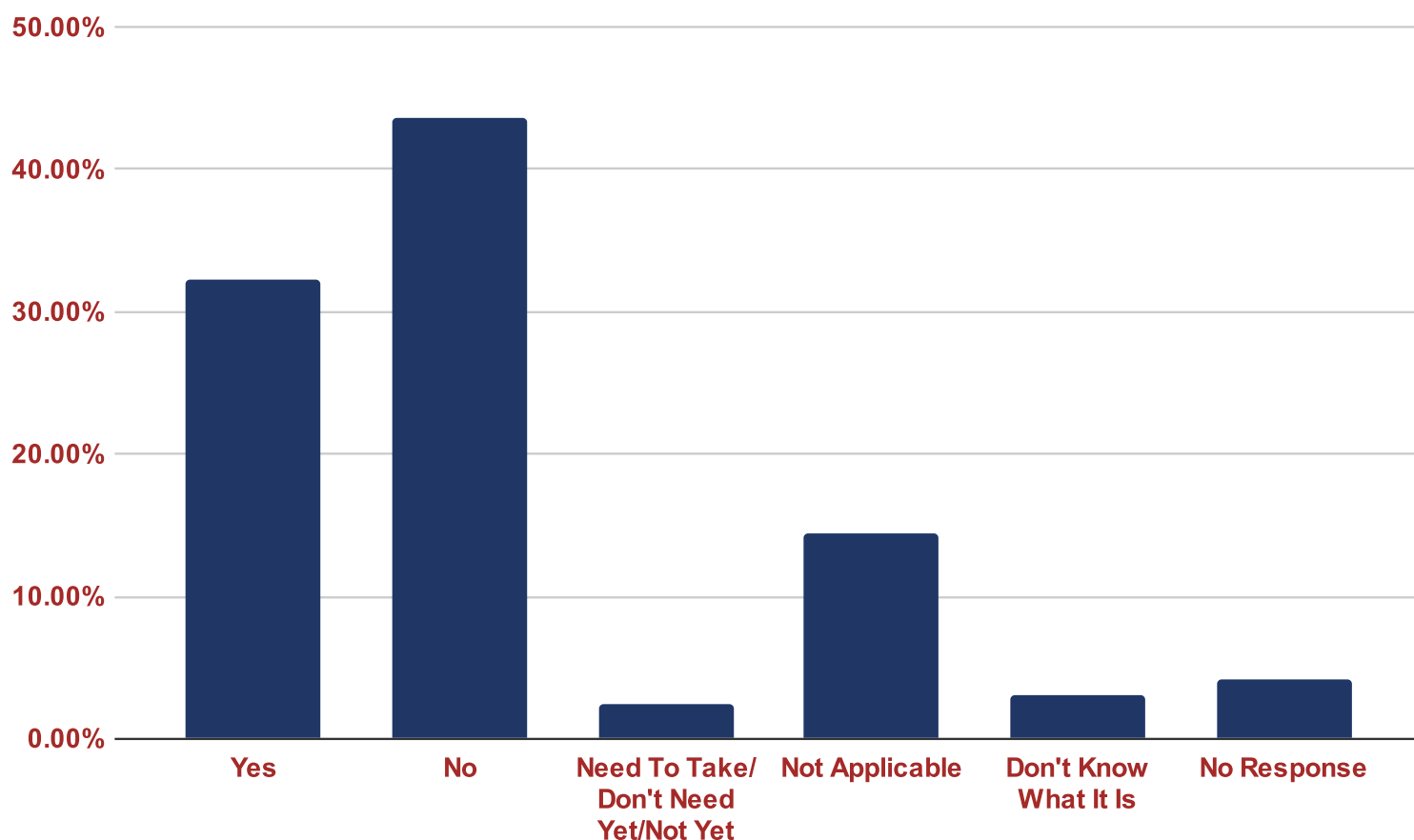
- Why are only families in the Autism Care Demonstration required to fill these out and not other EFMP families?
- How is this information used?
- Who has access to this information?
- How will this information affect the service member?
- What does this information have to do with my child getting the services they need?
- What does my sex life have to do with my child's therapy?

## Additional Concerns

- Families WILL lose services if they do not take these assessments
- Test is very intrusive and offensive
- Test is humiliating
- Families feel targeted and attacked
- It is unacceptable for TRICARE/DHA to mandate these assessments
- It is not a valid assessment for autism services.
- It is another barrier to access services
- Respondents have been brought to tears completing these parent assessments
- Mental health should be addressed by doctors not an insurance company/health benefit
- Families commented that completing this assessment has caused more stress and anxiety than their child's diagnosis or any other assessment they have ever done
- Violation of family's privacy
- Test requirement appears designed to drive families out of the program
- The questions do not reflect life of a military family or a family affected by autism
- The questions do not allow families to clarify the true source of their stress or skip questions that do not apply

# QUESTION 8

Have you had a difficult time finding a provider to complete the PSI4/SIPA assessment?



*“Yes! We only had one clinician in our remote [location] that could do it and they weren't in network. We we're out \$800 out of pocket just to be able to continue care!! Tricare NEVER reimburses the full amount and they are the ones requiring it.”*

\*\*Participants in the ACD take the Parent Surveys every 6 months.

# QUESTION 8 SUMMARY

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## Have you had a difficult time finding a provider to complete the PSI4/SIPA assessment?

### Yes

- 32.3% (54 out of 167 respondents)
- Quote "A 4 hour drive. 4. Hour. Drive. "
- Quote "Yes! Only a couple places in our area and they all have LONG (about a year) waitlists."
- Quote "Yes it took 2 months for the assigned company to respond."
- Quote "It was very difficult and took a lot of work on our end. Tricare was no help."

### No

- 43.7% (73 out of 167 respondents)
- Quote "I believe our BCBA is going to give it but she [is] uncomfortable already. "
- Quote "No but it is very uncomfortable for the staff to administer because of the nature of the questions"

### Need to take/Don't Need Yet/Not Yet

- 2.4% (4 out of 167 respondents)

### NA

- 14.4% (24 out of 167 respondents)
- Response was "N/A" or a comment they had not taken it.

### Don't know what it is

- 3% (5 out of 167 respondents)

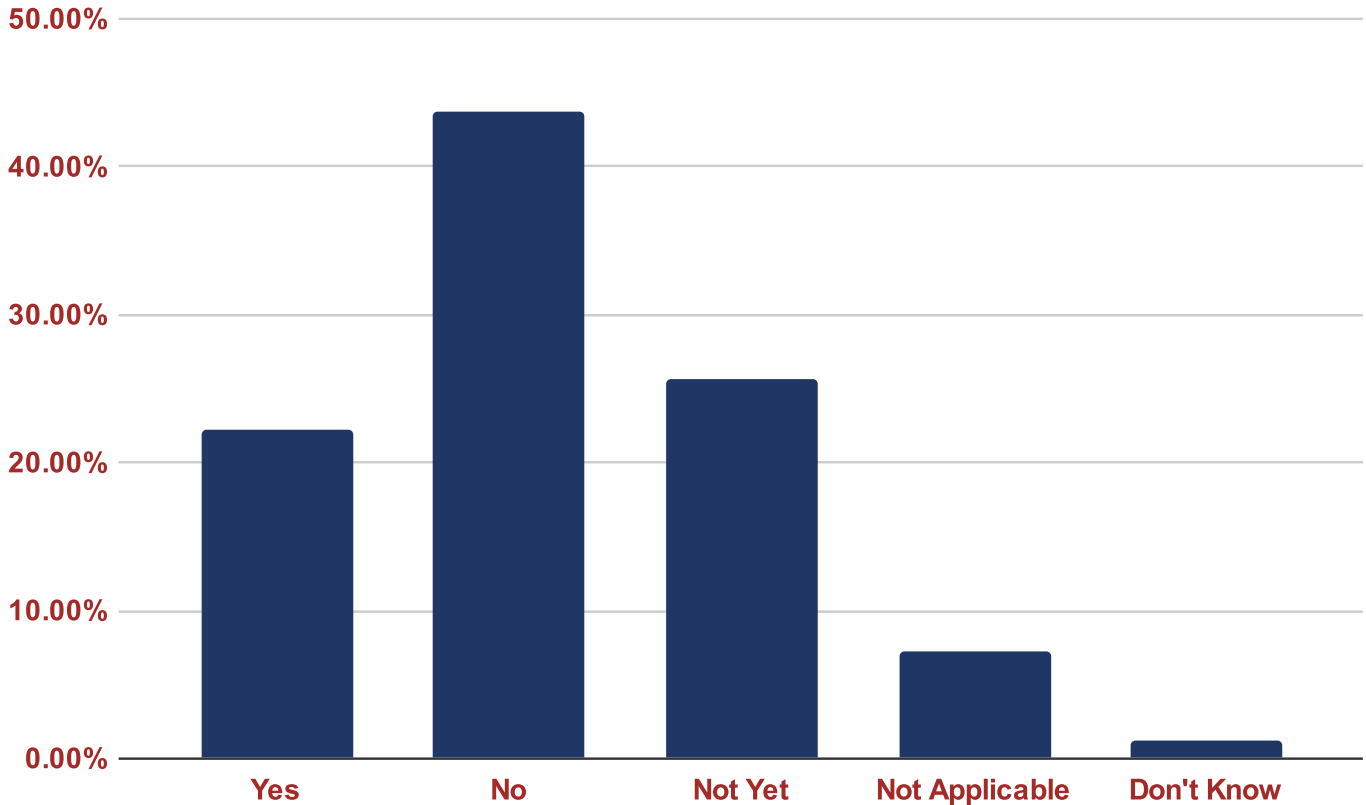
### No Response

- 4.2% (7 out of 167 respondents)
- question was left blank



# QUESTION 9

Has your provider dropped TRICARE as an insurance causing you to seek out a new provider due to these changes?



\*See page 27 for further breakdown of No, Not Yet and NA responses\*

*"Several companies we tried to go through turned us away because of TRICARE and this new policy. They said they were no longer treating TRICARE patients."*

# QUESTION 9 SUMMARY

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**Has your provider dropped TRICARE as an insurance causing you to seek out a new provider due to these changes?**

## Yes

- 22.2% (37 out of 167 respondents)
- Quote "Our previous provider and a provider we were waitlisted for are now no longer taking [TRICARE] clients, but are keeping the ones they have. One is a nation wide provider "
- Quote "Yes, they have advised me on how to utilize Medicare"
- Quote "My two boys are being forced to find a new provider and we are unable to find one."

## No

- 43.7% (73 out of 167 respondents)
- Quote "My provider no longer wants to take anymore [TRICARE] patients and they are.... still waiting to be paid"
- Quote "No, thankfully my daughter has a clinic that is committed to the children."
- Quote "No but I am worried that they will."
- Quote "No. However they have cut services making ABA significantly less impactful and positive for my child."

## Not Yet

- 25.7% (43 out of 167 respondents)
- Quote "Not yet but we were informed we not be renewed due to [TRICARE] changes "
- Quote "They have told us if the changes continue they will most likely drop our insurance provider in the near future."
- Quote "Not yet, but they warned us they may due to issues with Humana/ [TRICARE] consistently making mistakes, not being able to correct mistakes after hours invested via phone to get them fixed."

## NA

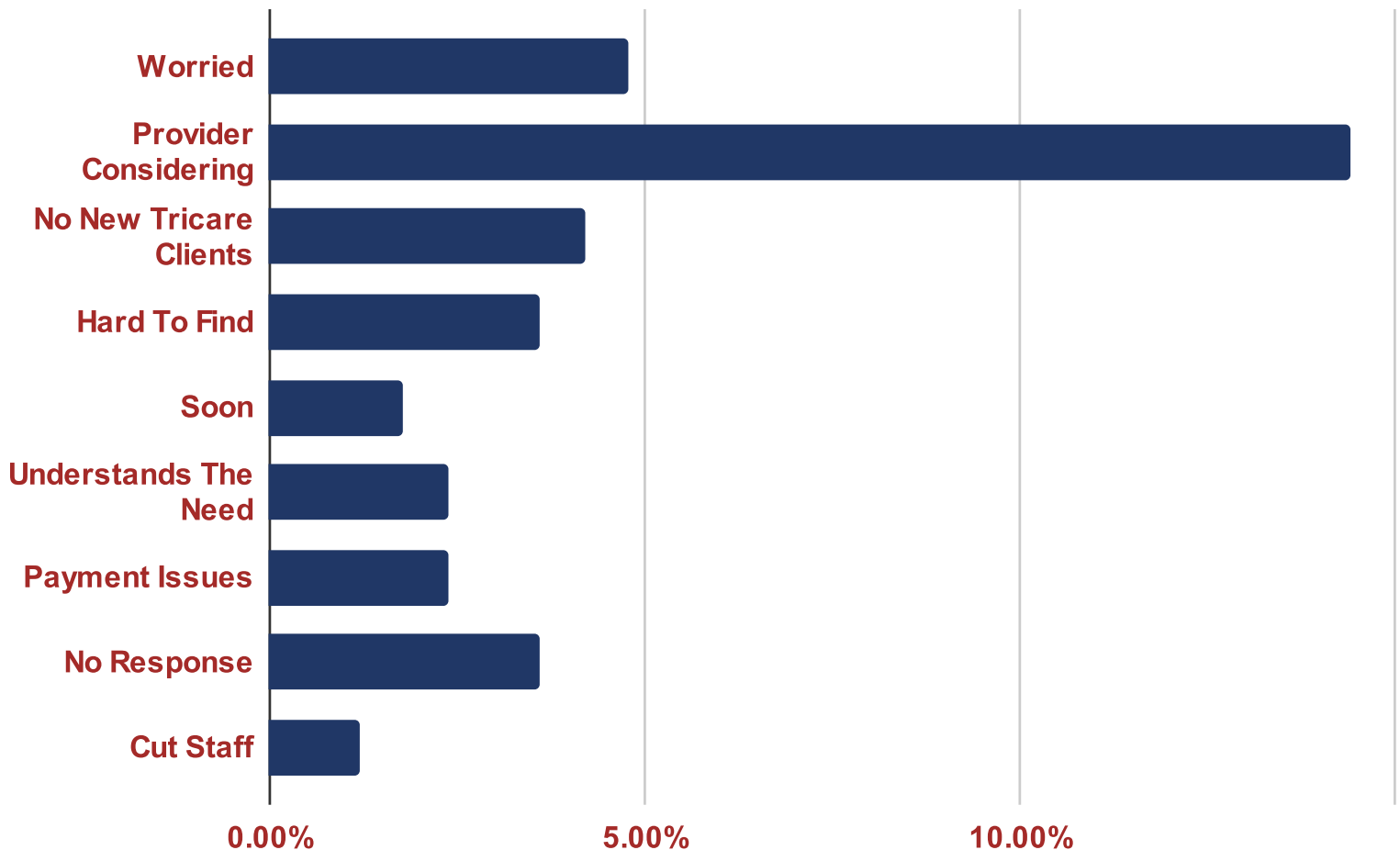
- 7.2% (12 out of 167 respondents)
- Response was "N/A" or a comment

## Don't know

- 1.2% (2 out of 167 respondents)

# QUESTION 9 BREAKOUT

Has your provider dropped TRICARE as an insurance causing you to seek out a new provider due to these changes?



*Breakdown of No, Not Yet or NA Responses from page 25*

\*This breakdown is a subset of the data contained inside 64 of the No, Not yet or NA answers from the Question Nine chart on page 25. It is based on comments the respondents made.

# QUESTION 9

## SUMMARY CONTINUED

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**Has your provider dropped TRICARE as an insurance causing you to seek out a new provider due to these changes?**

Note: For the No/Not Yet/NA responses we further identified the following concerns broken out of 64 of the comments

### Worried

- 4.8% (8 out of 167 respondents)
- Worried their provider will drop TRICARE

### Provider Considering

- 14.4% (24 out of 167 respondents)

### No New Tricare Clients

- 4.2% (7 out of 167 respondents)
- Provider is keeping them for now but will not take new TRICARE clients

### Hard to find

- 3.6% (6 out of 167 respondents)
- Providers taking TRICARE are hard to find

### Soon

- 1.8% (3 out of 167 respondents)

### Understand the need (of providers to drop TRICARE)

- 2.4% (4 out of 167 respondents)

### Payment Issues

- 2.4% (4 out of 167 respondents)

### No Response

- 3.6% (6 out of 167 respondents)

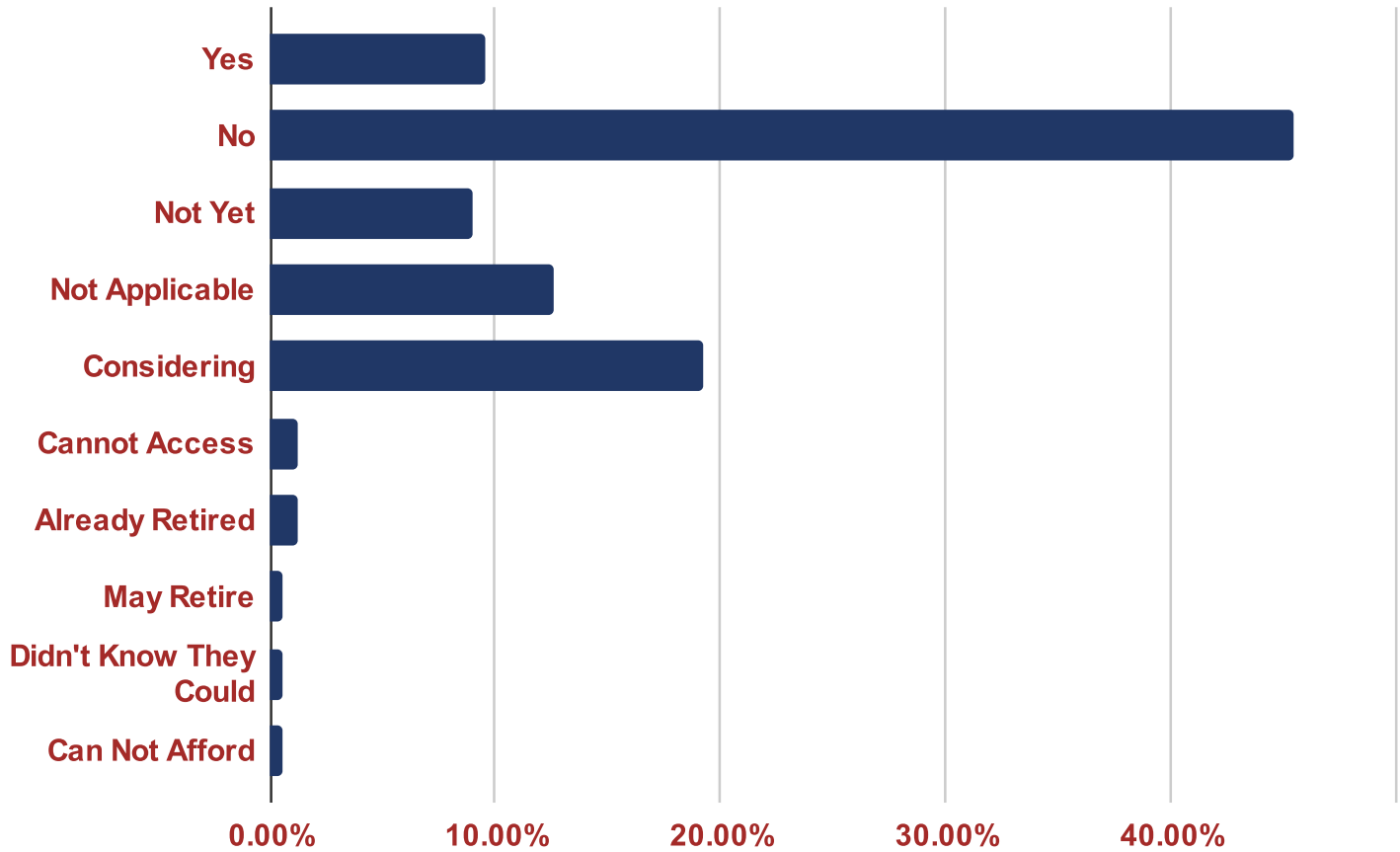
### Cut Staff

- 1.2% (2 out of 167 respondents)



# QUESTION 10 SUMMARY

Are these changes causing you to remove your child from the Autism Care Demonstration? If so, why?



\*See page 30-31 for greater transparency of "Yes", "No" and "Considering" responses\*

*"Not yet- we will still do it.... I would lose my career for my children to make sure they have what they need. ABA has been instrumental in helping them."*

# QUESTION 10

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## Are these changes causing you to remove your child from the Autism Care Demonstration? If so, why?

### Yes

- 9.6% (16 out of 167 respondents)
- Of 16 yes responses only 1 did not comment
  - 1 - yes, lost school/community support (0.6%)
  - 5 - yes, because of PSI/testing and changes (3.0%)
  - 2 - yes, doesn't cover needs (1.2%)
  - 1 - yes, too restrictive (0.6%)
  - 2 - yes, no providers available due to changes (1.2%)
  - 2 - yes, due to changes (1.2%)
  - 1 - yes, dropped ABA (0.6%)
  - 1 - yes, retiring (0.6%)
  - 1 - yes, finding therapy elsewhere (0.6%)

### No

- 45.5% (76 out of 167 respondents), 33 gave comments below
  - 4 - no, because no other options available (2.4%)
  - 5 - no, but will keep fighting (3.0%)
  - 1 - no, waiting to retire (0.6%)
  - 9 - no, need the therapy/can't afford to self pay (5.4%)
  - 2 - already disagree with use of ABA (1.2%)
  - 1 - no because that is what DHA wants (0.6%)
  - 1 - if we leave military it will be to find insurance (0.6%)
  - 1 - no, but may lose provider (0.6%)
  - 1 - no, filling gaps in therapy themselves (0.6%)
  - 4 - no but therapy less effective due to changes (2.4%)
  - 1 - no, but lost hours (0.6%)
  - 2 - no, but making it hard (1.2%)
  - 1 - no, leaving for better insurance (0.6%)

### Not Yet

- 9.0% (15 out of 167 respondents)

# QUESTION 10 CONTINUED

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## Are these changes causing you to remove your child from the Autism Care Demonstration? If so, why?

### NA

- 12.6% (21 out of 167 respondents)
- no response, responded NA or response not clear

### Considering

- 19.2% (32 out of 167 respondents), 31 gave comments below
  - 4 - considering, because so limited (2.4%)
  - 2 - considering, because of limited providers available (1.2%)
  - 3 - considering, due to changes (1.8%)
  - 1 - considering, if able get secondary insurance (0.6%)
  - 1 - considering, may hire private (0.6%)
  - 1 - considering, due to PSI and changes (0.6%)

### Cannot Access Services

- 1.2% (2 out of 167 respondents)

### Already Retired

- 1.2% (2 out of 167 respondents)

### May Retire Early

- 0.6% (1 out of 167 respondents)

### Didn't Know They Could

- 0.6% (1 out of 167 respondents)

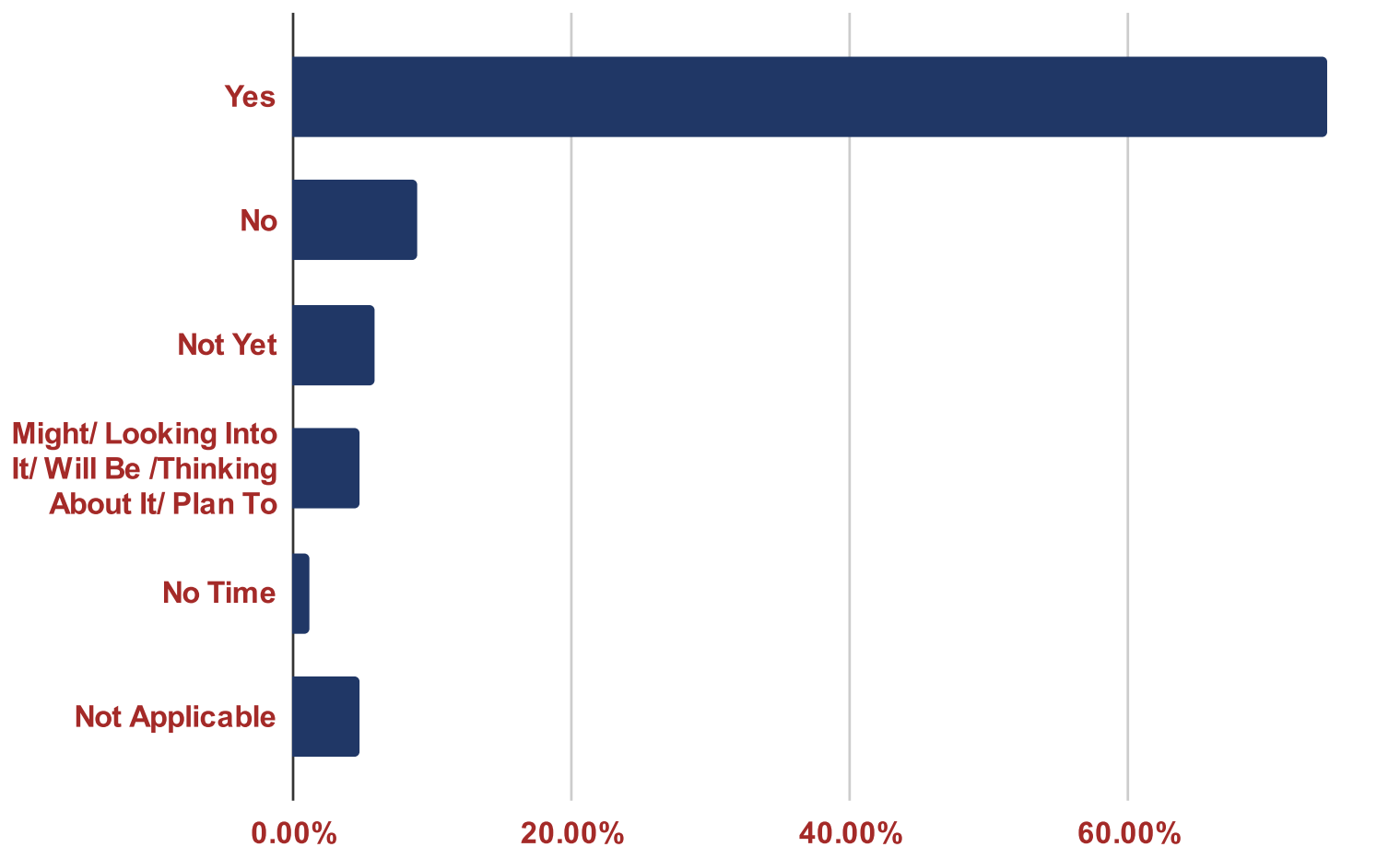
### Cannot Afford To

- 0.6% (1 out of 167 respondents)

# QUESTION 11

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Have these changes encouraged you to speak with your state representatives?



*"Yes, absolutely. We sacrifice so much, our entire family, and we deserve better. TRICARE MUST do better."*



# QUESTION 11 SUMMARY

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## Have these changes encouraged you to speak with your state representatives?

### Yes

- 74.3% (124 out of 167 respondents)
- Quote "Yes. I have sent dozens of letters. I only received a response from one congressman and it was a form letter response. So maddening."
- Quote "Yes I've feel like the DHA isn't hearing my voice so I have reached out."
- Quote "Yes and a lawyer"
- Quote "Yes and request a congressional inquiry."

### No

- 9% (15 out of 167 respondents)

### Not Yet

- 6% (10 out of 167 respondents)
- Quote "Not yet, I've never found it to be helpful in any other matter."

### Might/Looking into it/Thinking about it/Plan to

- 4.8% (8 out of 167 respondents)
- Quote "I'm planning to reach out to command and state reps"

### No Time

- 1.2% (2 out of 167 respondents)
- Quote "I'm too tired as a special needs mom for all these extra measures"

### NA

- 4.8% (8 out of 167 respondents)

# RESPONDENT ADDITIONAL COMMENTS

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There is no chart available for this question due to all answers being in comment form. Comments are broken out into the most commonly expressed concerns, where the main issues and feelings voiced by respondents are then summarized.

## Military Families Feel Betrayed

- Quote: "Military families have enough stressors being in the military with special needs children. Many of us have no family or support near due to our duty assignments. Every time TRICARE make it difficult to receive services for our children it is like a slap in the face. Our families serve this country and put duty first. It would be nice to receive that same service and duty with our health care."
- Stated that the changes are discriminatory, unjust and cruel
- Fear data has been manipulated in examination of ABA efficacy
- View these changes as saving money at the expense of the most vulnerable
- Noted they were not consulted or allowed to give feedback on the changes
- Pleading to reverse the changes
- Expressed feeling like their service to the country is now at the expense of their family member with autism and is causing increased stress.

## Increased Hardships Due to Changes

- Find ABA therapy is harder to access with fewer providers accepting TRICARE
- Find changes have greatly affected access to care
- Find changes have increased their paperwork and legwork burdens
- Children are regressing and having more problems

## Parent Surveys Causing Families Stress

- How is DHA using the results?
- Why is this only required for autism/ABA and not all EFMP families?
- Expressed feeling targeted
- Find stress assessments themselves are the reason for their stress
- Find the Assessments upsetting, insulting, invasive and humiliating
- Quote "The current policy violates mental health parity regulations. While TRICARE is not subject to mental health parity laws, I do not believe military personnel should have less protections than their civilian neighbors."

# RESPONDENT ADDITIONAL COMMENTS CONTINUED

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## Our families and children need help

- Stated they are losing the support and medical care for their children.
- Expressed changes have affected the mental health of their children.
- Families are feeling lost and helpless.
- Quote "Military families face challenges everyday. Families with autistic children, even more. Removing are benefits make our children suffer. Please stop punishing my child because of a disability he can't control."
- Quote "WHY are we making our children with special needs suffer?"

## Family Voices Left Unheard

- Want to be valued as stakeholders and included in policy decisions within the ACD
- Want decision makers to seek value family feedback
- Want transparency in the decisions to make these changes and evaluation of their impact
- Want the Defense Health Agency to listen to their concerns and respond to messages they have sent in regards to the changes and their children's therapy.

## Miscellaneous

- Stated they want other services be offered to families that do not want to use ABA therapy.
- Stated they are thankful for the collection of this data
- Service members pass up promotions to retire for the sake of their children

*"Military families face challenges everyday. Families with autistic children, even more. Removing are benefits make our children suffer. Please stop punishing my child because of a disability he can't control."*

# CONCLUSION

The changes made to the Autism Care Demonstration (ACD) are hurting autistic individuals which the program is designed to help and the families who support them. Not only is stress growing for their families, but these changes are increasing their isolation and financial burdens. Service members are considering leaving the military. The loss of services due to the ACD changes will have lifelong implications for these individuals, their families, and the military's future as a whole.

The Parent Stress Tests are highly upsetting, causing concern about how they are being used and who has access to them.

Families do not know how the information in these surveys is relevant to their family members needs and why therapy is contingent on their completion. The lack of transparency and invasiveness of these surveys makes families strongly opposed to their use and there is an outcry to discontinue them.

Families feel betrayed, lost, hopeless and angry. They are begging for a voice in the determinations that affect their loved ones and their families. They are demanding transparency in how these determinations are made and how information is being used. Families want these changes reversed and service members want to feel like they can serve this country without worry that it is at the cost of their family's medical and mental health.

Exceptional Families  
of the Military



One Community,  
One Voice

# SURVEY TAKEAWAYS

*Families want the ACD changes reversed so their loved ones get the services they need and deserve. Military families sacrifice enough of their lives to the military, their children's medical care should not be one of them.*

*Families want the invasive and humiliating Parent Stress Tests discontinued.*

*Families want ABA therapy services to be returned to them for community and school settings.*

*Families want ABA therapy to be able to work on important life skills such as toileting again.*

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*Families feel there is a lack of transparency and communication from the DHA/TRICARE*

*Families feel that TRICARE is erecting barriers that prevent access to ABA therapy and limits it in ways that make it ineffective.*

*Families feel lost and do not know how to help their autistic family members with all of the ACD changes.*

*Families are struggling to get services because ABA providers are dropping TRICARE beneficiaries due to the ACD changes.*

*Families would like access to alternative therapies when ABA is not appropriate for their family's needs.*

*Families stated that ABA services should be protected, not restricted.*

*Families feel that the DHA/TRICARE have failed their children.*



# AUTISM FAMILY ADVOCACY COMMITTEE COMMENT

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To the families that have responded to this survey, and affected by the Autism Care Demonstration changes:

We want to say thank you for sharing your voices, concerns, fears and frustrations with us. We hear you and we will continue to advocate for you and your family!

Sincerely,  
The Autism Family Advocacy Committee



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the Military



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