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# PATH TO DIAGNOSIS AND TREATMENT

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A Survey of Parents of  
Children with Autism



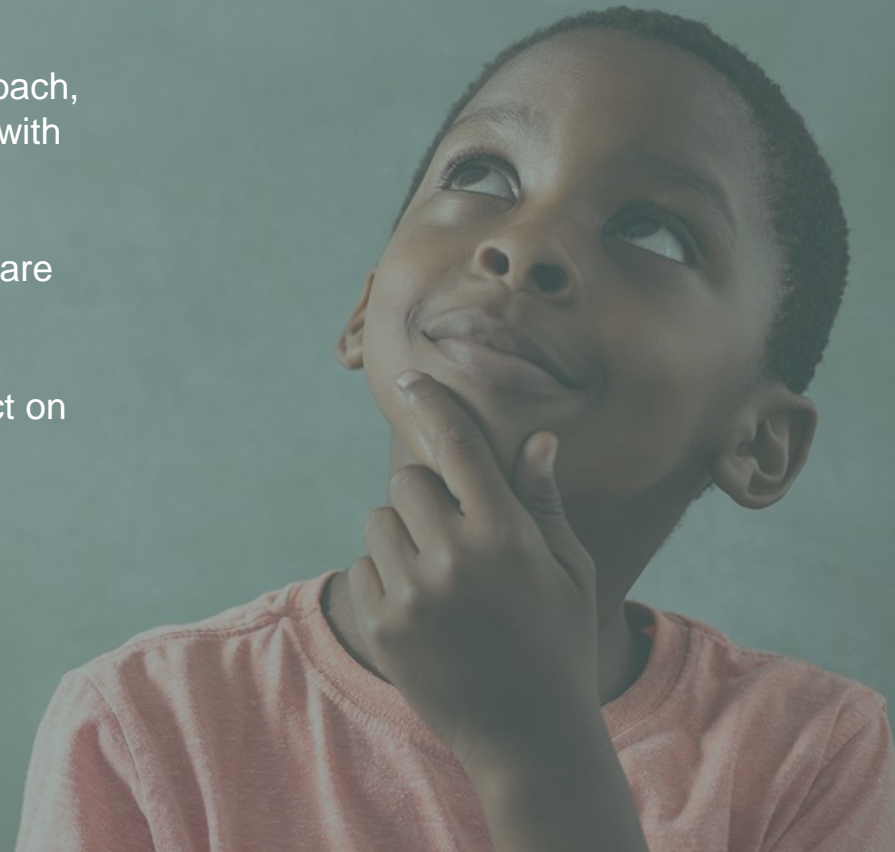



# OUR APPROACH

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Centria Autism fielded a survey among 1,000 parents of children with Autism Spectrum Disorder (ASD) ages 10 years or younger to ask questions focused on:

- 1) The diagnosis/treatment gap for children with autism;
- 2) The significant unmet need in providing an evidence-based approach, like ABA therapy, for the education and development of children with autism at an early-stage;
- 3) Desired and expected treatment goals for their child and if those are being met through current treatment methods; and
- 4) How societal views and general perceptions are having an impact on their child's ability to integrate into mainstream society.





# METHODOLOGY & DEMOGRAPHICS

- An online survey was conducted during March 2019 among 1,000 parents of children age 10 years or younger who have been diagnosed with ASD.
- Survey invitations were sent out via email by Wakefield Research. The median survey length was 15 minutes. Respondents received a personal incentive for their participation.

	TOTAL
<b>CHILD GENDER</b>	
Male	69%
Female	31%
<b>CHILD AGE (mean years)</b>	6.6
<b>PARENT GENDER</b>	
Male	32%
Female	68%
<b>HOUSEHOLD INCOME</b>	
<\$25,000	7%
\$25,000-\$49,999	19%
\$50,000-\$99,999	53%
\$100,000+	19%
Prefer not to answer	2%

	TOTAL
<b>MARITAL STATUS</b>	
Married	74%
Separated/Divorced/ Widowed	10%
Single, never married	16%
<b>RACE/ETHNICITY</b>	
White, non-Hispanic	66%
Black, non-Hispanic	12%
Hispanic	15%
Other	7%
<b>REGION</b>	
Northeast	19%
South	41%
Midwest	21%
West	19%

# EXECUTIVE SUMMARY 1

## THE PATH TO DIAGNOSIS

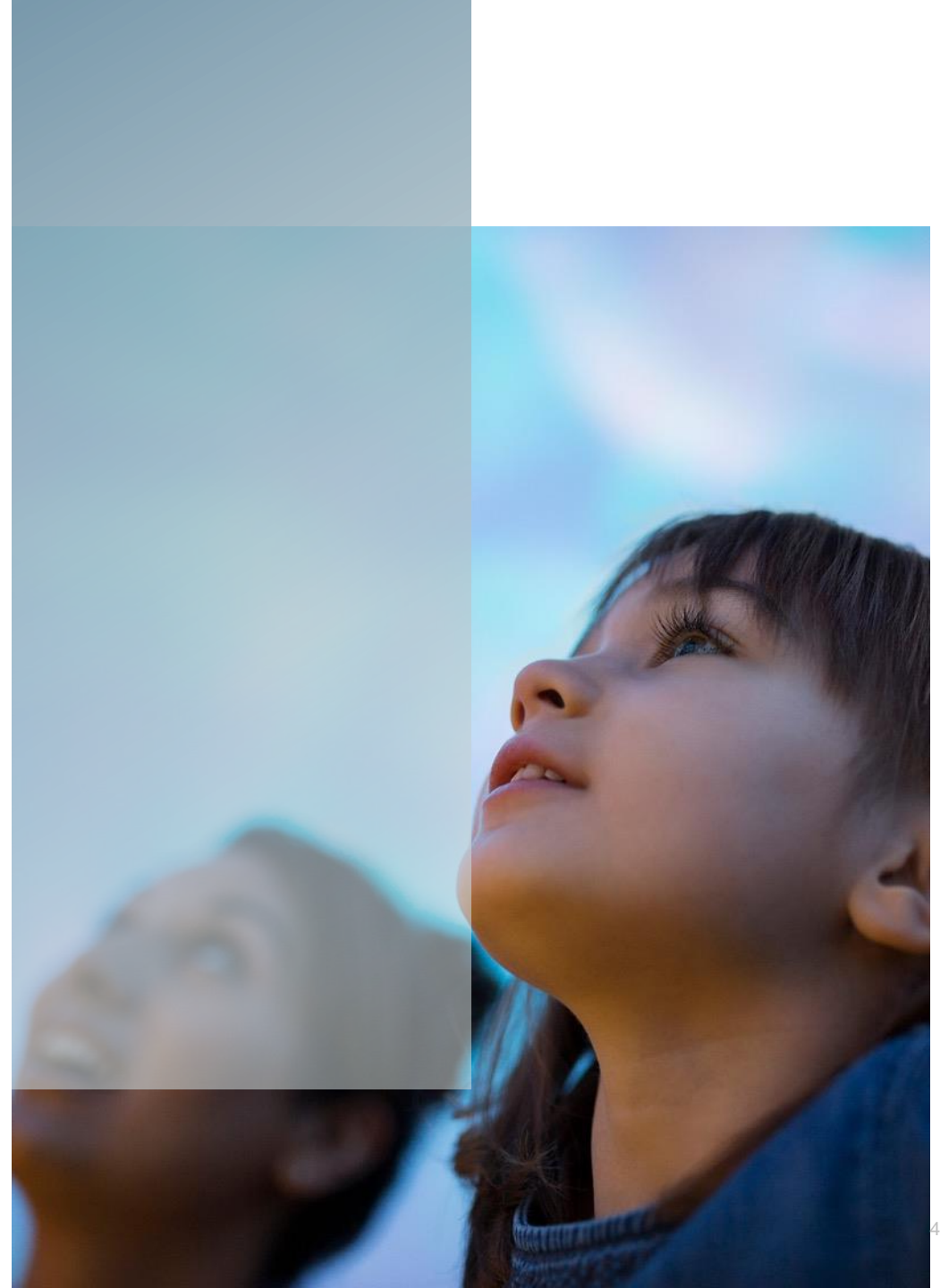
The path to diagnosis can be a long and difficult one. **On average, there is a 13-month gap from when parents first suspect a developmental issue until their child receives an official diagnosis.** Delays are caused by both informational issues (parents searching for information and not knowing who to go to) and process issues (waiting for insurance and scheduling multiple appointments). **Nearly all parents find the path to diagnosis stressful, and more than half encountered at least one pitfall—receiving conflicting information, getting a different or incorrect diagnosis first, or being told their child “would grow out of it.”** Despite setbacks, parents maintain a positive image of their child’s diagnosing provider as being empathetic, caring, and supportive.

## THE PATH TO TREATMENT

While the path to treatment is shorter than the one to diagnosis, most parents agree that finding the right treatment is overwhelming. **On average, there is a 3-month delay between diagnosis and treatment with the biggest barriers being long wait lists, issues with insurance coverage and costs, and finding a therapist.** Other psychological barriers may also be at play with many parents not being sure what they should do and worrying about making the wrong choices. Parents want more direction from, and coordination between, health care providers. They also want clear discussion guides that explain insurance coverage as well as the benefits and barriers of the various treatment options.

## TREATMENT CHOICES

There appears to be quite a bit of trial and error in choosing treatments. Parents are looking for many factors when they choose an option **with the most important being the availability of school readiness programs and cost.**



# EXECUTIVE SUMMARY 2

## TREATMENT EXPERIENCES

Parents report that their children are getting about 90% of their prescribed therapy, and more than two-thirds are extremely or very satisfied with their current therapy choice. Almost half believe their child has made a lot of progress. **Nearly half of those with children showing less progress attribute it to not yet having enough time in therapy for improvements to show.** Successful therapy looks different to different parents, but the key themes that emerge are achieving normalcy, making social connections, and happiness.

## CAREGIVER EXPERIENCES

**Caring for a child with ASD adds the equivalent of a part-time job (20 hours a week) to a parent's already busy life.** It has the most impact on work/career advancement, but also negatively impacts parents' relationship with their spouse or significant other. Accordingly, parents want more financial and emotional support. **In fact, 86% of parents wish they had a care coordinator—someone who they could turn to that would help them coordinate their child's treatment and care.**

## MEDIA & TECHNOLOGY

Parents are almost evenly divided in their perceptions of autism in the media with 1/3 finding portrayals very or mostly realistic, 1/3 calling them somewhat realistic, and 1/3 say they are not realistic. Parents praise shows that depict realistic images of people with ASD but are quick to point out that given how broad the spectrum is, most portrayals at the upper or lower ends did not match their experiences.

Parents were overwhelmingly supportive of new technology. **About eight out of ten think voice-activated home speakers like Siri or Alexa could provide socialization benefits to children with autism** and a similar percent and even more are interested in learning more about how virtual reality simulations can lead to better outcomes during confrontations between people with ASD and police or other authority figures.





# THE PATH TO DIAGNOSIS



# TIME TO DIAGNOSIS



- On average, parents first suspect a developmental issue at 33 months.
- They discuss their suspicions with a health professional at 38 months.
- They receive an official diagnosis at 46 months.
- **The overall gap from first suspecting an issue to diagnosis is 13 months.**
- **It takes an average of 8.3 medical visits to receive an official diagnosis.**

**SUSPICION**  
(33 months)

**DIAGNOSIS**  
(46 months)

**DISCUSSION**  
(38 months)

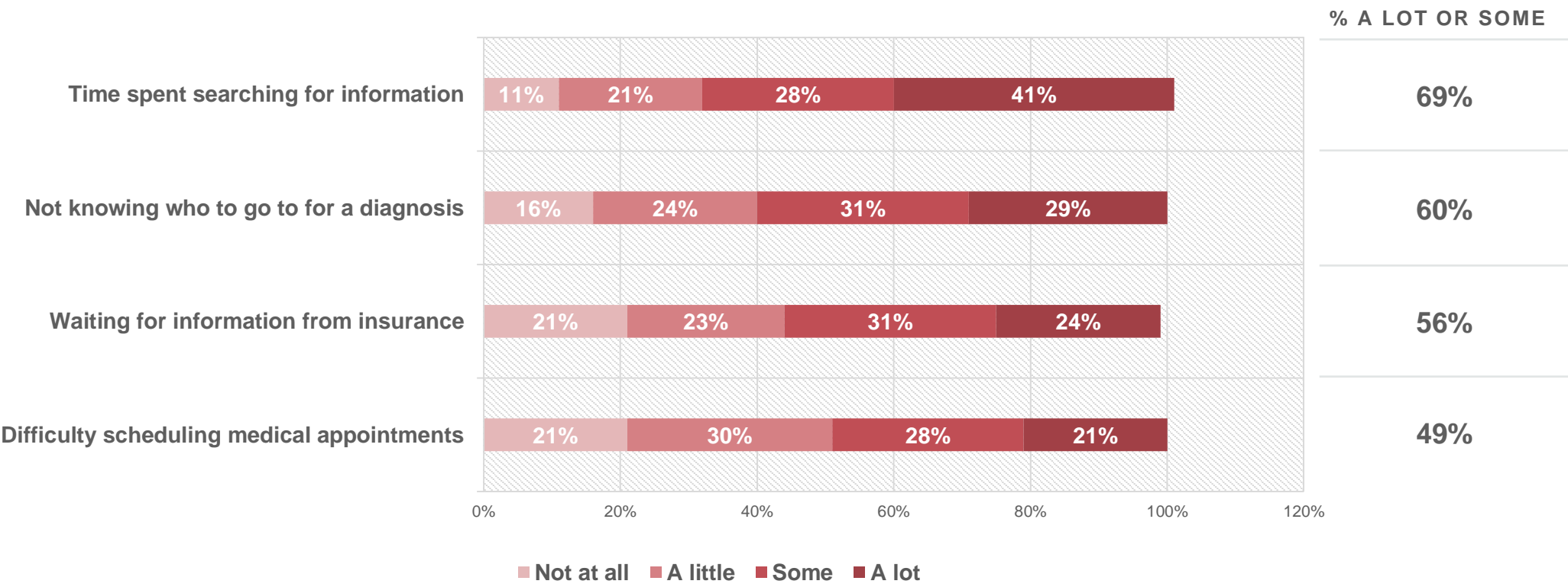
1+ YEAR DIAGNOSIS GAP



# WHAT CONTRIBUTES TO THE GAP?

More than two-thirds of respondents say that searching for information contributed to the diagnosis gap.

*How much did each of the following factors contribute to the delay from the time you suspected an issue to official diagnosis?*

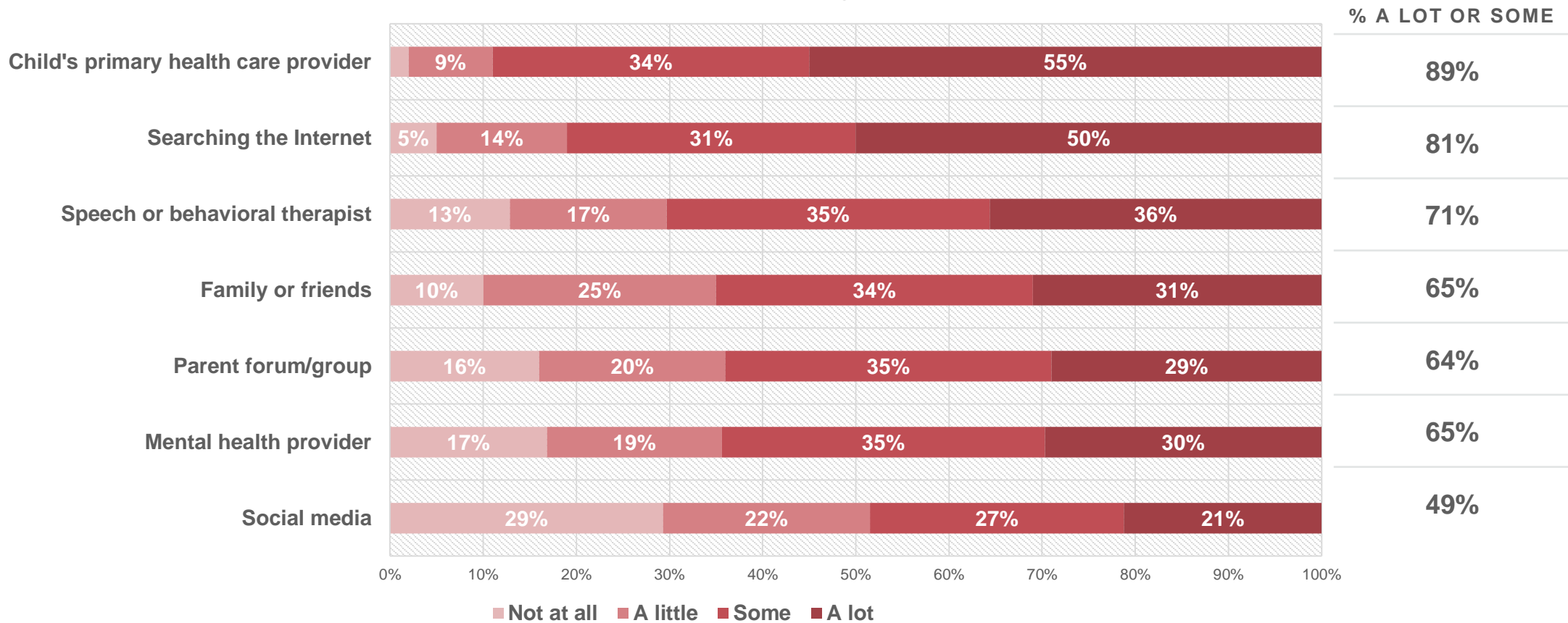




# INITIAL INFORMATION SOURCES

When parents first suspect a developmental issue, their **top sources** for information are their child's health care provider and the Internet.

*When you first suspected your child had a developmental issue, how much did you use each of the following for information?*



# PROCESS EVALUATION

## 58%

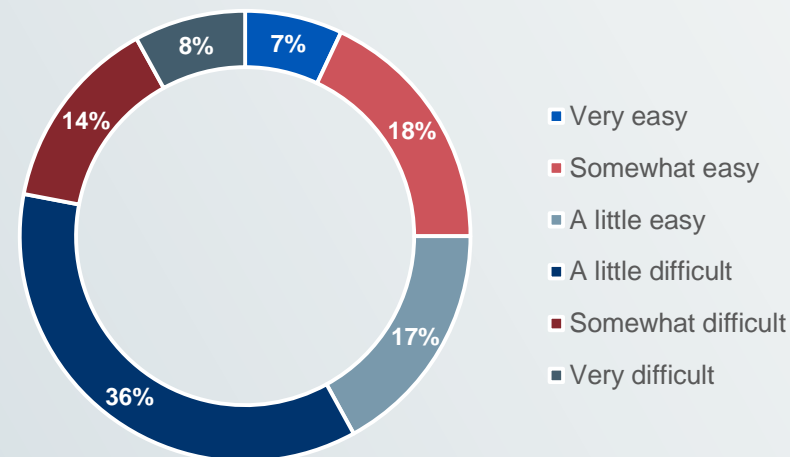
of parents said the process of getting their child diagnosed was difficult

Parents with a longer diagnosis gap (1+ years) were more likely than those with a smaller gap to indicate the process was difficult (64% vs. 51%)

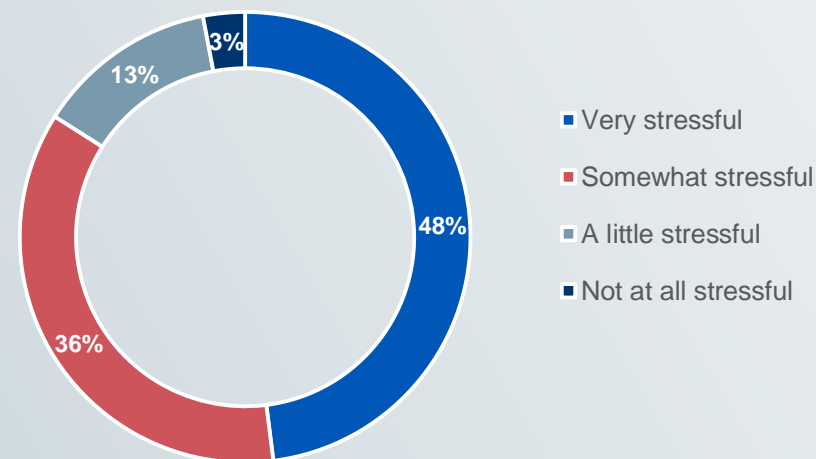
## 84%

said it was very or somewhat stressful

*How would you rate the process of getting your child diagnosed?*

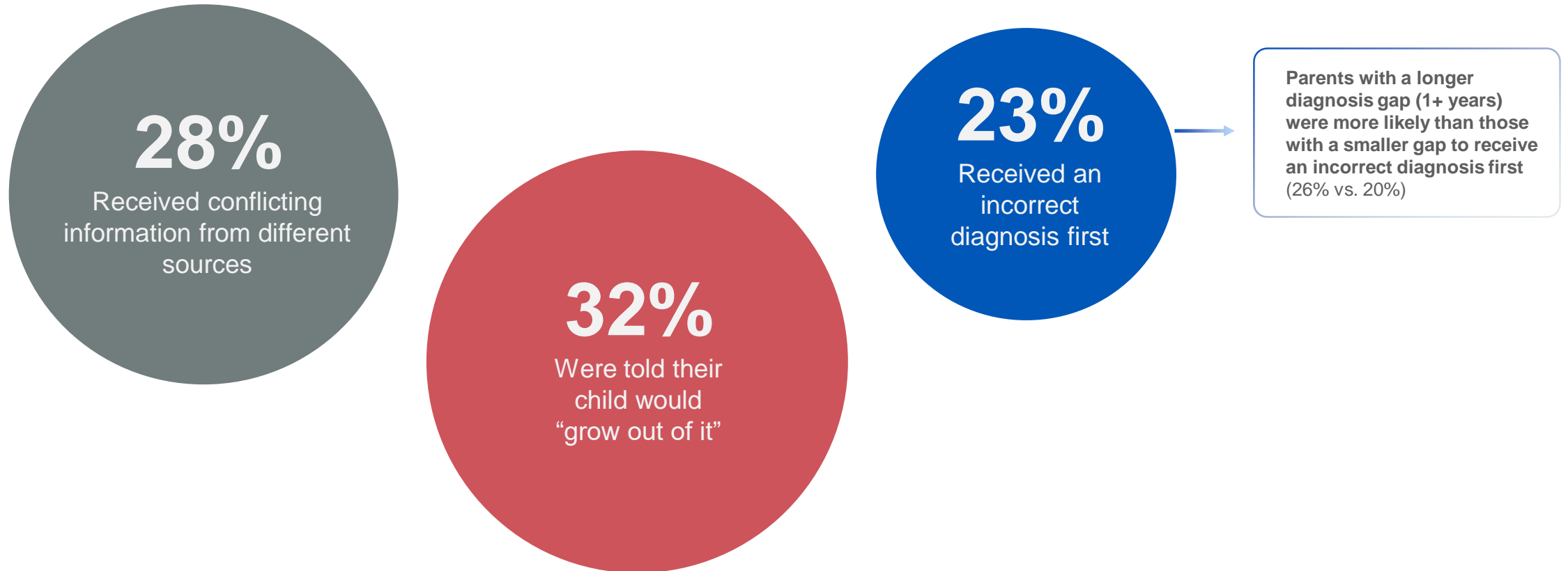


*How would you rate the process of getting your child diagnosed?*



# PROCESS PITFALLS

Although more than 7 out of 10 parents received referrals to therapists\* while trying to get their child diagnosed, **55% encountered issues:**



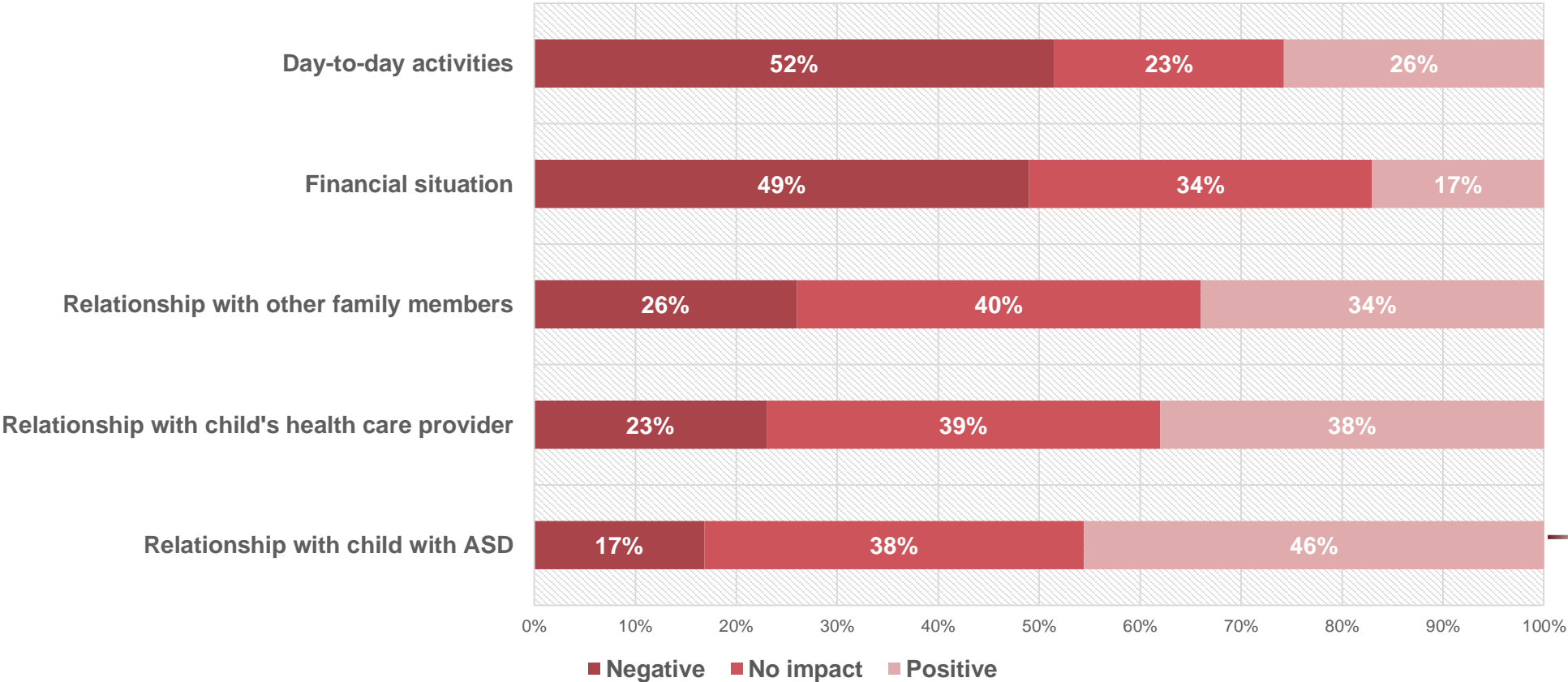
\*Received referral to a behavioral, speech, occupational, or physical therapist



# PROCESS IMPACTS

About half of respondents report negative impacts on their day-to-day activities and finances, while 26% felt their family relationships were negatively impacted by the diagnosis process.

*How did the process of getting your child diagnosed affect each of the following?*

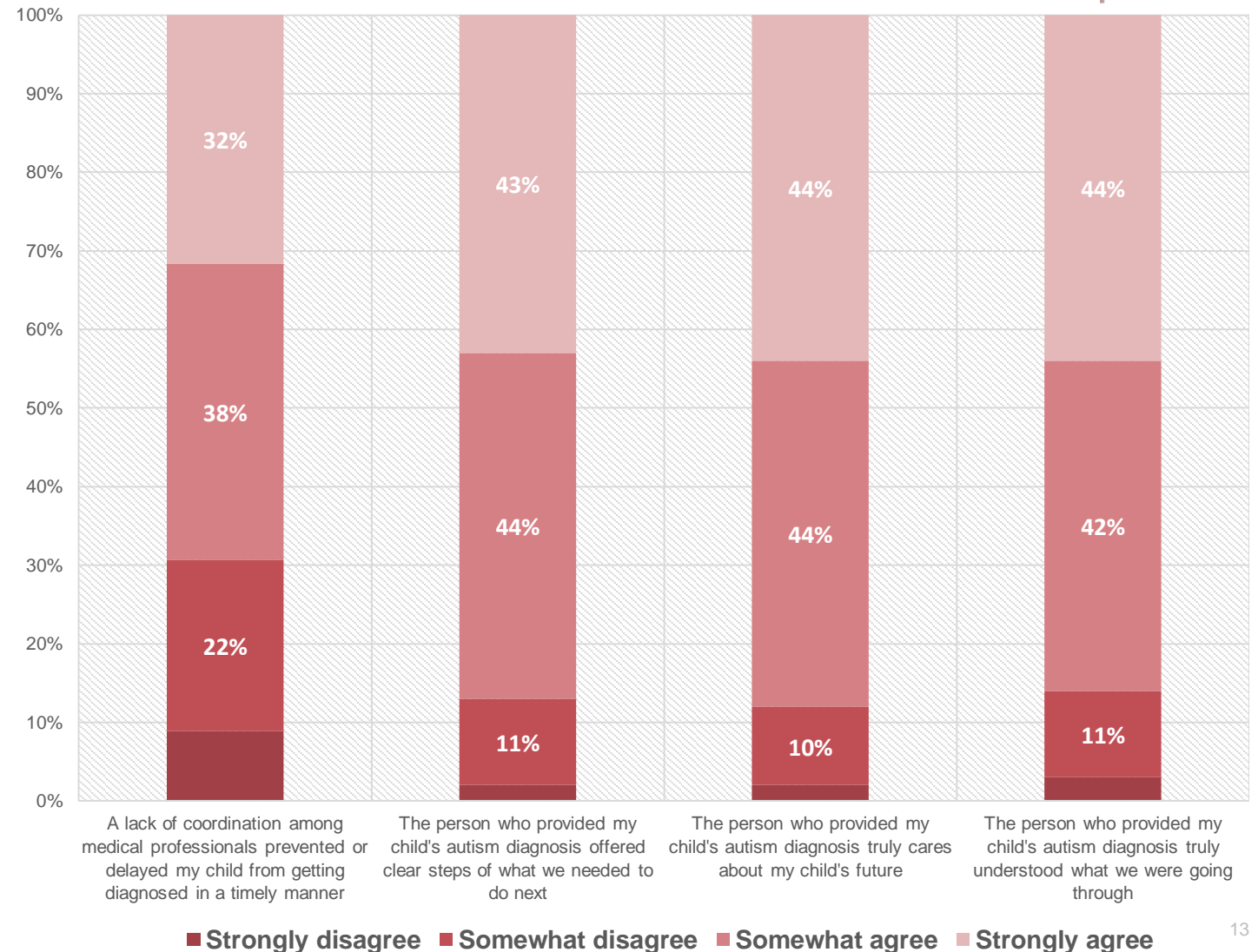


Parents whose children are currently receiving ABA Therapy are more likely than others to say the diagnosis process had a positive impact on their relationship with their child with ASD (54% vs. 44%)

# PERCEPTIONS OF PROVIDERS

7 out of 10 parents think a lack of coordination among medical professionals contributed to the delay in diagnosing their child.

Despite setbacks in the diagnosis process, most parents believe the person who diagnosed their child truly understands and cares about them.



# THE PATH TO TREATMENT

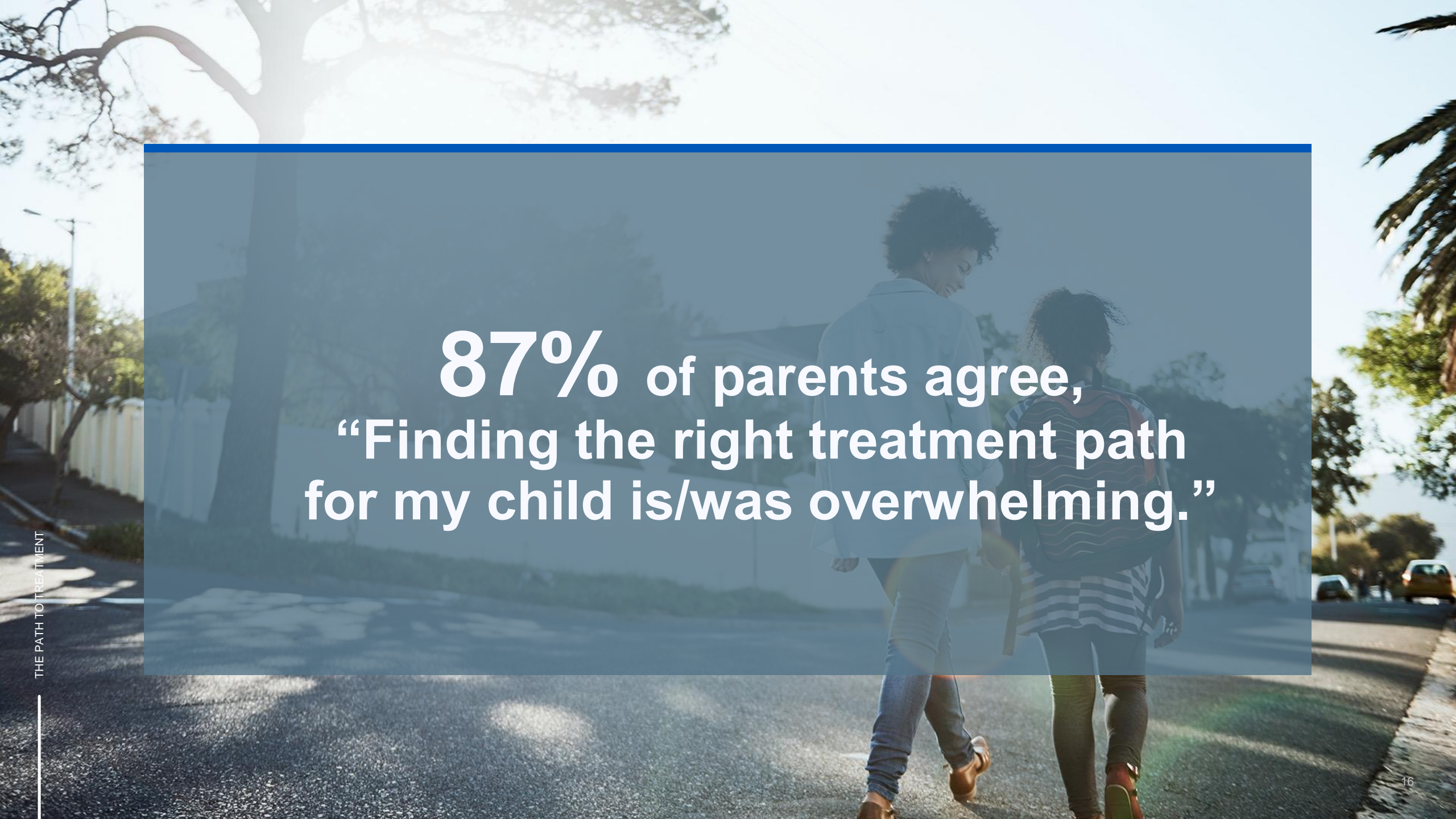




# TIME TO TREATMENT

- On average, parents received an official diagnosis when their child was 46 months old and began treatment when their child was 49 months old.
  - **The average delay between diagnosis and treatment is 3 months.**
- However, some parents (13%) began treatments prior to official diagnosis. If those parents are not included in the analysis, the average treatment delay is 5 months.



A woman and a child are walking away from the camera on a paved path. The woman is on the left, wearing a light blue jacket and jeans, looking down at the child. The child is on the right, wearing a striped shirt and a backpack, walking towards the right. The background shows a sunny street with trees and a white fence. A large blue semi-transparent rectangle is overlaid on the image, containing white text.

**87% of parents agree,  
“Finding the right treatment path  
for my child is/was overwhelming.”**

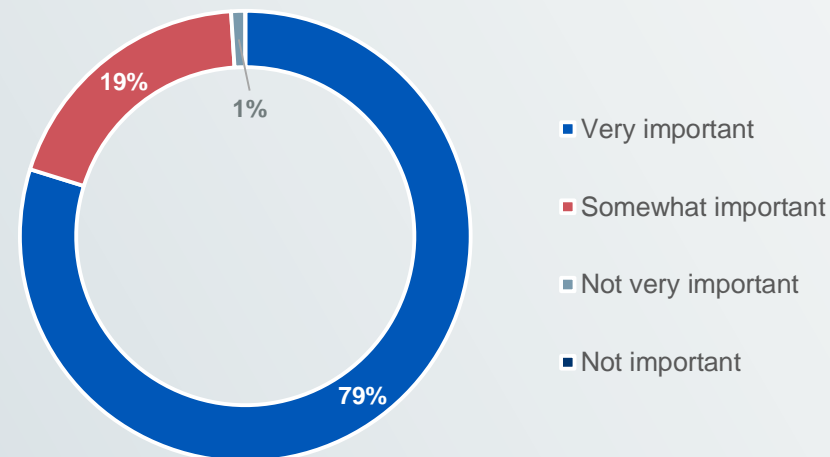
# PERCEPTIONS ABOUT TREATMENT

**8 out of 10 parents agree that early intervention for children with autism is very important** and they also believe it is important for parents or other family members to participate in the treatment.

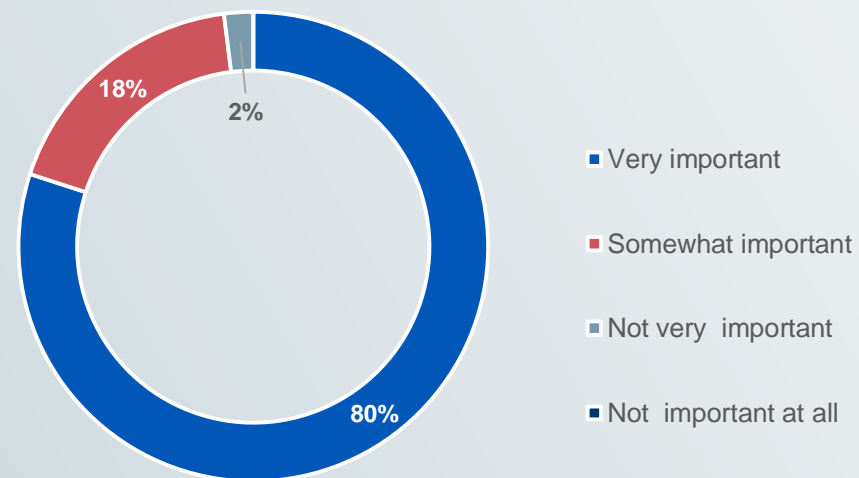
On average, they believe the ideal age to begin treatment is around age 3 (mean=37 months).

**95% agree that the earlier a child with autism receives treatment, the better the treatment outcomes.**

*How important is early intervention for children with autism?*



*How important is it for parents or other family members to participate in a child's treatment for autism?*





# FINDING TREATMENT

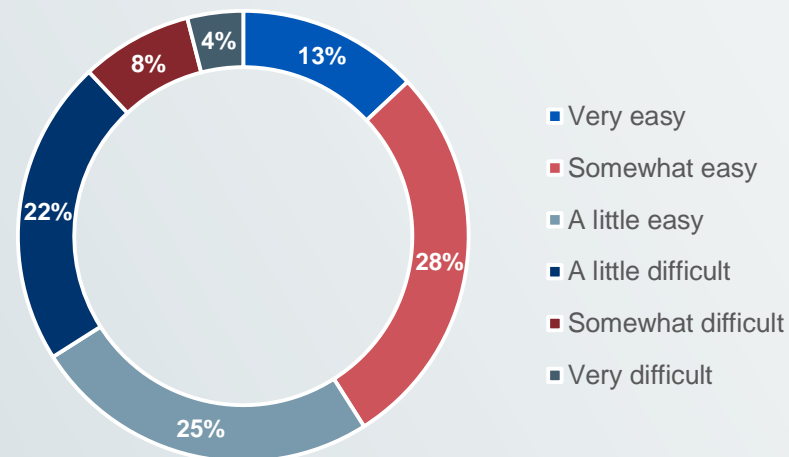
One-third of parents said it was difficult to learn about locally-available treatment options.

**Parents with a treatment delay were more likely than those without a delay to indicate the process was difficult (39% vs. 30%).**

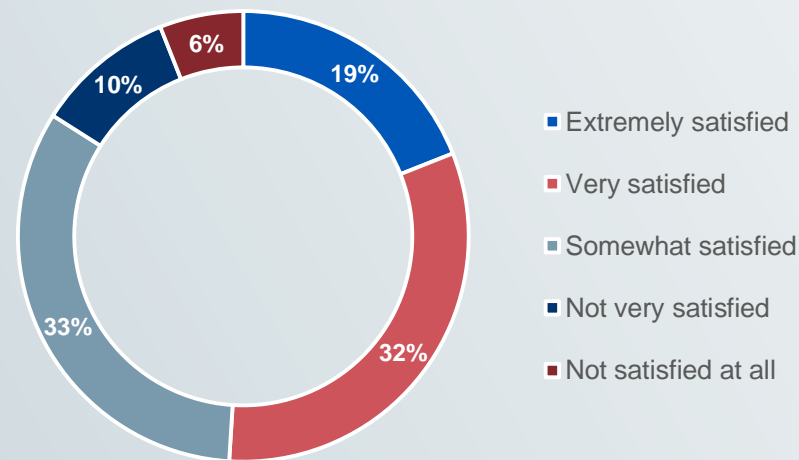
Half are extremely or very satisfied (51%) with the number and type of available options.

**Parents with a treatment delay were less likely than parents without a delay to be extremely/very satisfied (47% vs. 56%).**

*How easy or difficult was it to learn about the treatment options available in your area for ASD?*



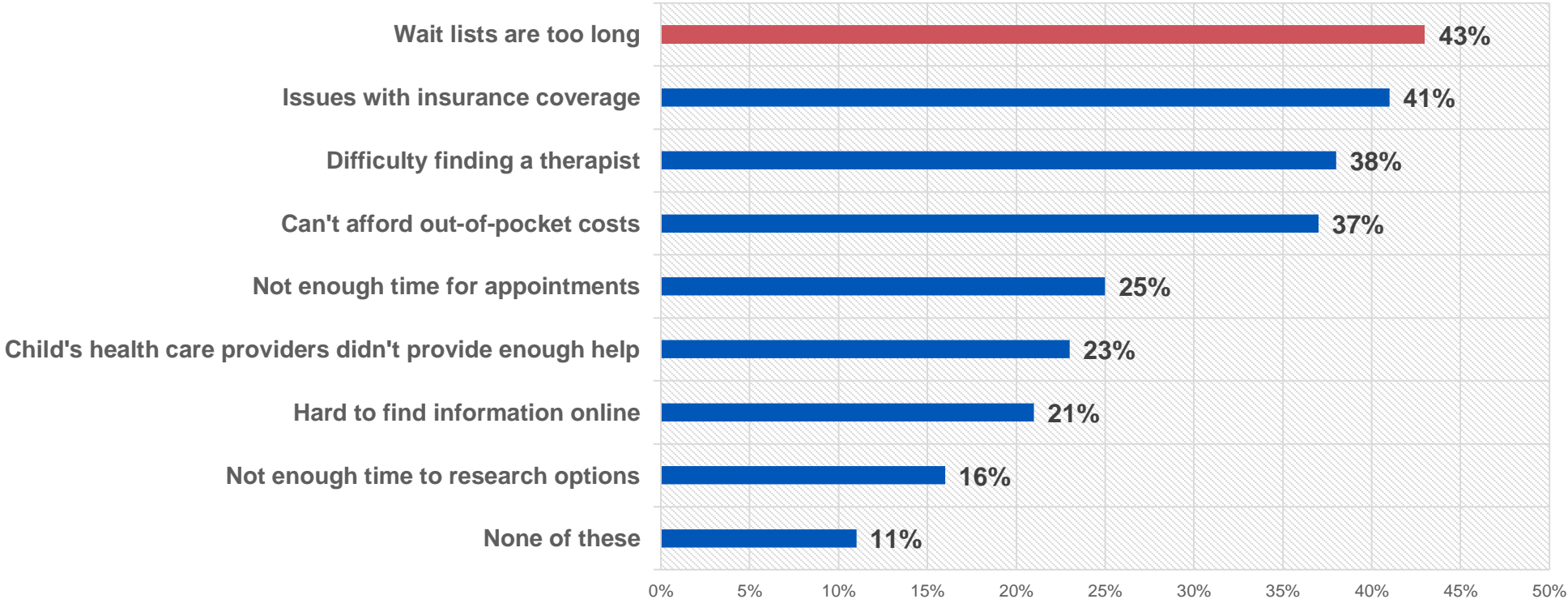
*How satisfied are you with the number and type of treatment options available for ASD in your community?*



# BARRIERS TO FINDING TREATMENT

The **top barriers** to finding a good treatment option are long wait lists, issues with health insurance coverage, and difficulty finding a therapist.

*Which, if any, of the following have made it difficult for you to find a good treatment option for your child? (Multiple selections)*



# PARENT VULNERABILITIES

More than 7 out of 10 parents indicated there's a constant struggle to get their child the help they need, with a similar number of parents worrying about making the right decision for their child's treatment plan.

**58%**

Feel they don't know  
what to do when  
making treatment  
choices

**60%**

Feel at a loss of  
how to best help  
their child

**72%**

Worry about making  
the wrong treatment  
choices

**76%**

Say it is a constant struggle  
to get their child the  
help they need

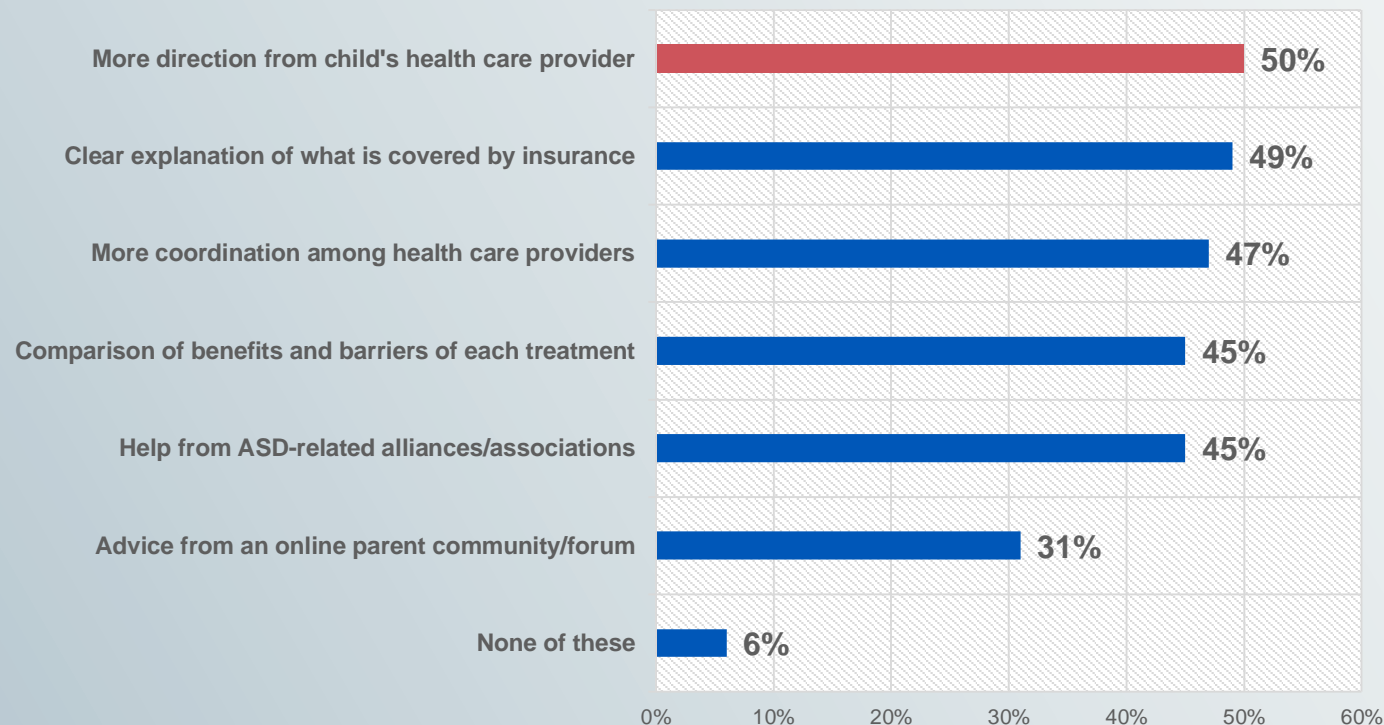


# PARENT NEEDS

Parents are most likely to say they need more direction from their child's pediatrician or other health care provider as well as clear insurance explanations.

**Parents whose children are currently receiving ABA Therapy are more likely than others to say choosing a treatment option would have been easier if there was more coordination among health care providers (58% vs. 44%).**

*What would have made the process of choosing a treatment option easier for you? (Multiple selections)*



# TREATMENT CHOICES





# TREATMENT AWARENESS, EFFECTIVENESS & USE

While more than **7 out of 10** parents have **heard of speech therapy and special education**, only about half have heard of ABA Therapy.

- Among those who have heard of ABA Therapy, **51% think it is very effective** and another 40% think it is somewhat effective.

	HEARD OF	VERY EFFECTIVE (% AMONG HEARD OF)	TRIED	CURRENTLY USE
Speech Therapy	76%	58%	60%	47%
Special Education	70%	49%	46%	37%
Social Skills Training	66%	57%	42%	31%
Physical Therapy	58%	46%	35%	23%
Complementary/Alternative Therapy	-	-	89%	22%
ABA Therapy	52%	51%	26%	18%
Cognitive Behavioral Therapy	55%	49%	24%	14%
Early Intervention Education	64%	63%	41%	18%
Psychotherapy Occupational Therapy	43%	53%	21%	13%

# WHAT DO YOU HOPE/THINK ABA THERAPY WILL DO FOR YOUR CHILD?

“ABA has brought my child from non-verbal to conversational and greatly increased her social abilities. I hope it continues to help her feel comfortable in new and challenging situations.”

“To help my child one day be able to care for himself, and learn to survive on his own.”

“Help him to cope. I don’t want to change who he is, I just want him to not get overwhelmed as much.”

“To get along with his family, and most importantly himself.”

“Limit problem behaviors and let him live a good life”

“Have my child show less symptoms and be able to better integrate into society without stigma attached.”

**“Give her a normal life”**

“I hope she will continue to build verbal skills and be able to communicate verbally and live a successful and happy life..”

“I hope it will boost her social skills and help her blend in with the neurotypical children.”



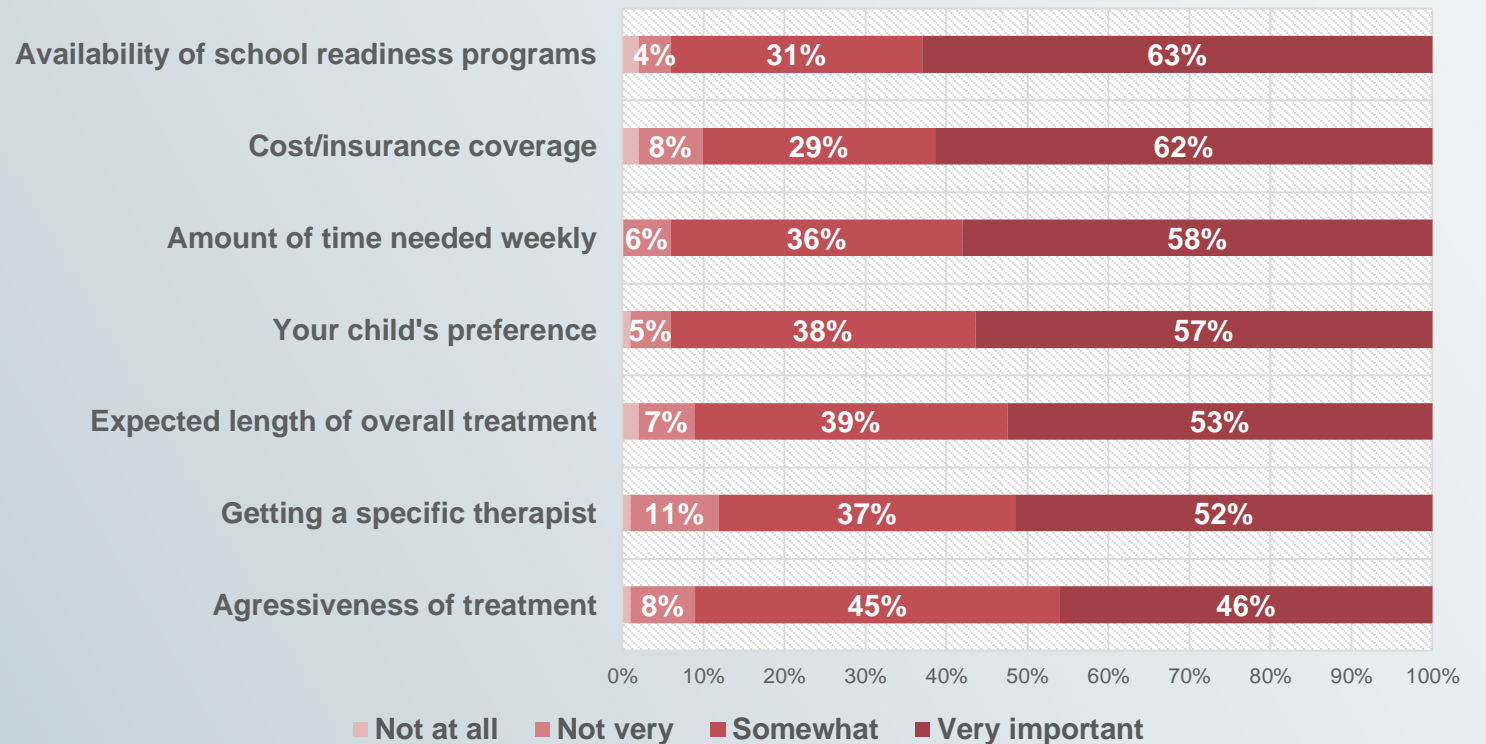


# IMPORTANCE OF TREATMENT FACTORS

A top priority when choosing treatment is the availability of school readiness programs—they are very important to more than 6 out of 10 parents.

- Parents whose children are currently receiving ABA Therapy are more likely than others to rate several factors as very important including cost/insurance coverage (69% vs. 60%), time (66% vs. 56%), and getting a specific therapist (60% vs. 50%).

*How important are each of the following aspects of the treatment you chose for your child?*



# TREATMENT EXPERIENCES

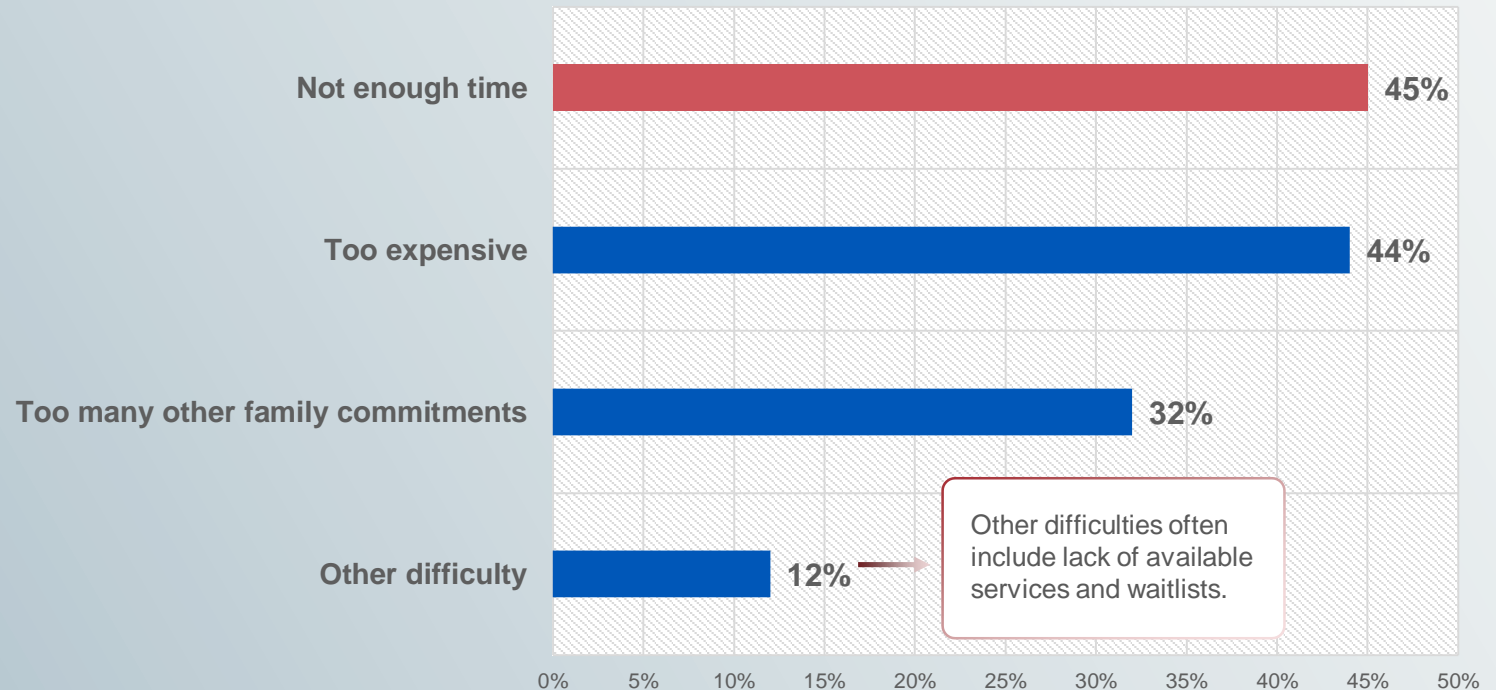
# AMOUNT OF TREATMENT

On average, parents say their child was prescribed 11 hours of treatment per week, but they currently receive 10 hours.

Parents whose children are currently receiving ABA Therapy say their children were prescribed an average of 17 hours and currently participate in 16 hours of treatment.

**Time and cost are the most likely reasons preventing children from receiving their full dose of treatment.**

*What, if anything, makes it difficult for your child to receive as much treatment as he or she was prescribed? (Multiple selections)*

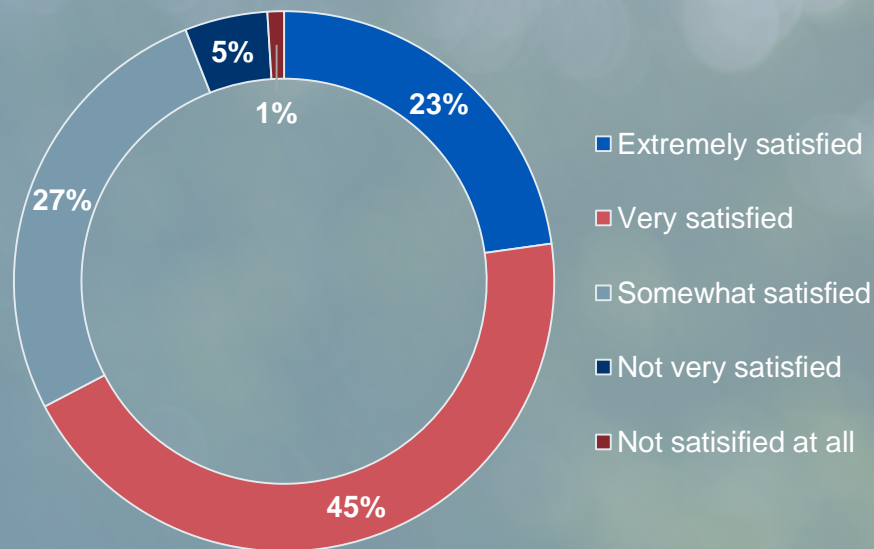




# SATISFACTION WITH TREATMENT

Despite barriers and complications, over **two-thirds of parents** are very or extremely satisfied with their child's current treatment.

*How satisfied are you with your child's current treatment?*





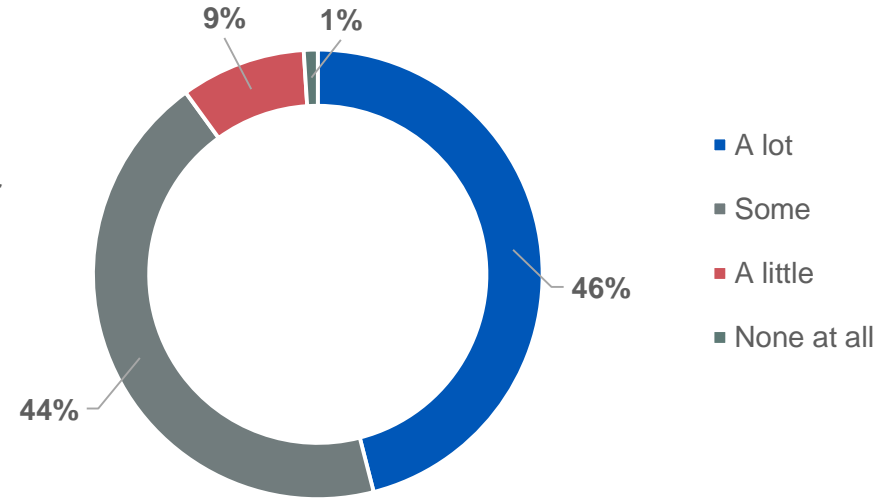
# TREATMENT PROGRESS

9 out of 10 parents say their child has made at least some progress in treatment.

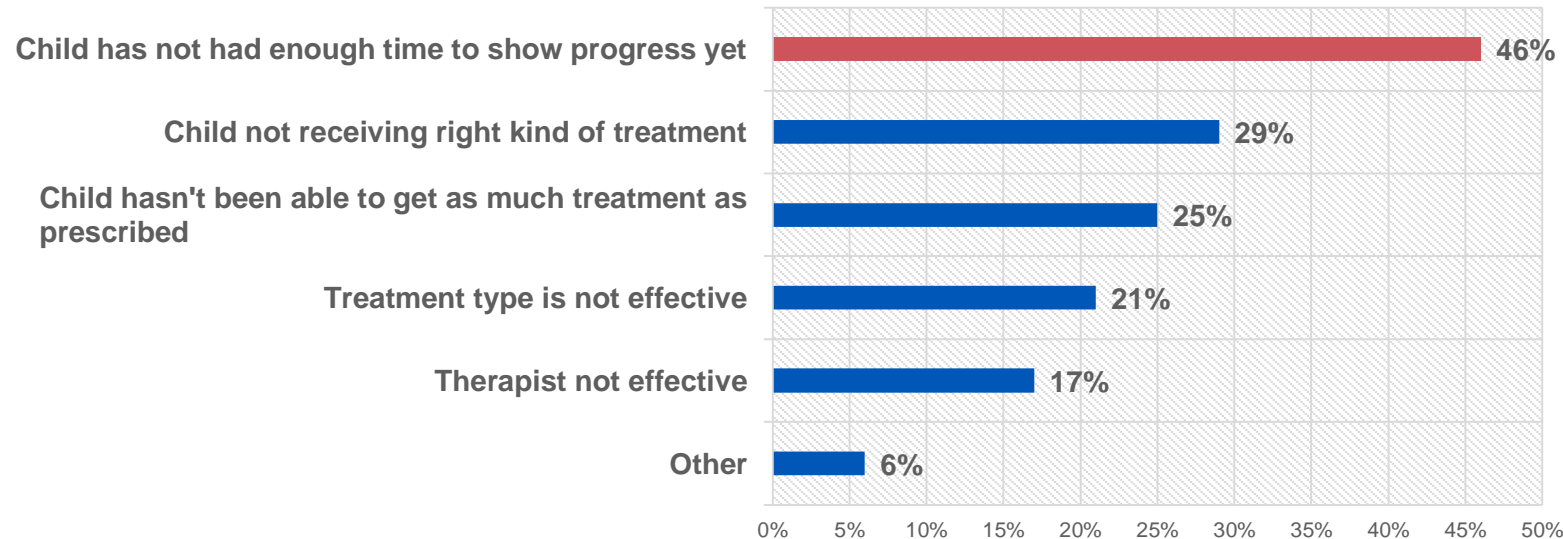
Parents whose children receive ABA Therapy are more likely than other parents to say their child has made a lot of progress (53% vs. 45%).

Top reasons for lack of progress are not having enough treatment yet and not having the right kind of treatment. “Other” reasons include switching therapists and contending with multiple diagnoses.

*To what extent has your child made progress in his or her treatment?*



*Why hasn't your child made a lot of progress in treatment? (Among those who didn't select "A lot" in previous question; Multiple selections)*



# TREATMENT SUCCESS

Successful therapy for the child looks different to every parent, but **the key themes that emerged include seeing their child achieve “normalcy,” make social connections, and be happy with him or herself.**

36%

Have a ‘normal life’

35%

Be happy with him or herself

27%

Meet their basic needs

32%

Have friends and meaningful relationships

32%

Be safe

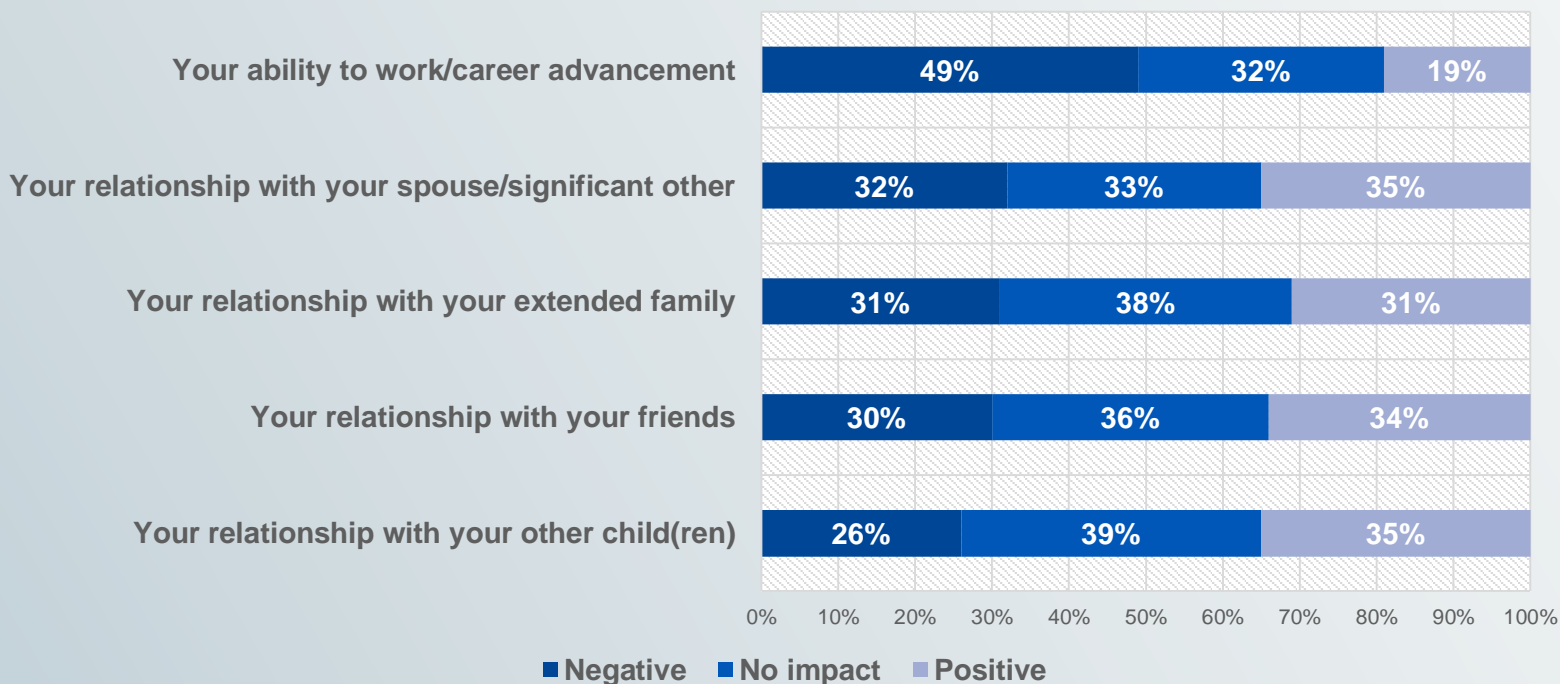
# CAREGIVER EXPERIENCES



# IMPACT TO CAREER & RELATIONSHIPS

- Half of parents say their child's ASD has negatively impacted their career.
  - Parents with a longer diagnosis gap (1+ years) are more likely to report negative impacts in all areas.
- Moms are more likely than dads to report negative impacts on their careers (53% vs. 41%) and their relationships with their spouses (34% vs. 27%) and their other children (28% vs. 20%).

*How has your child's autism impacted each of the following?*

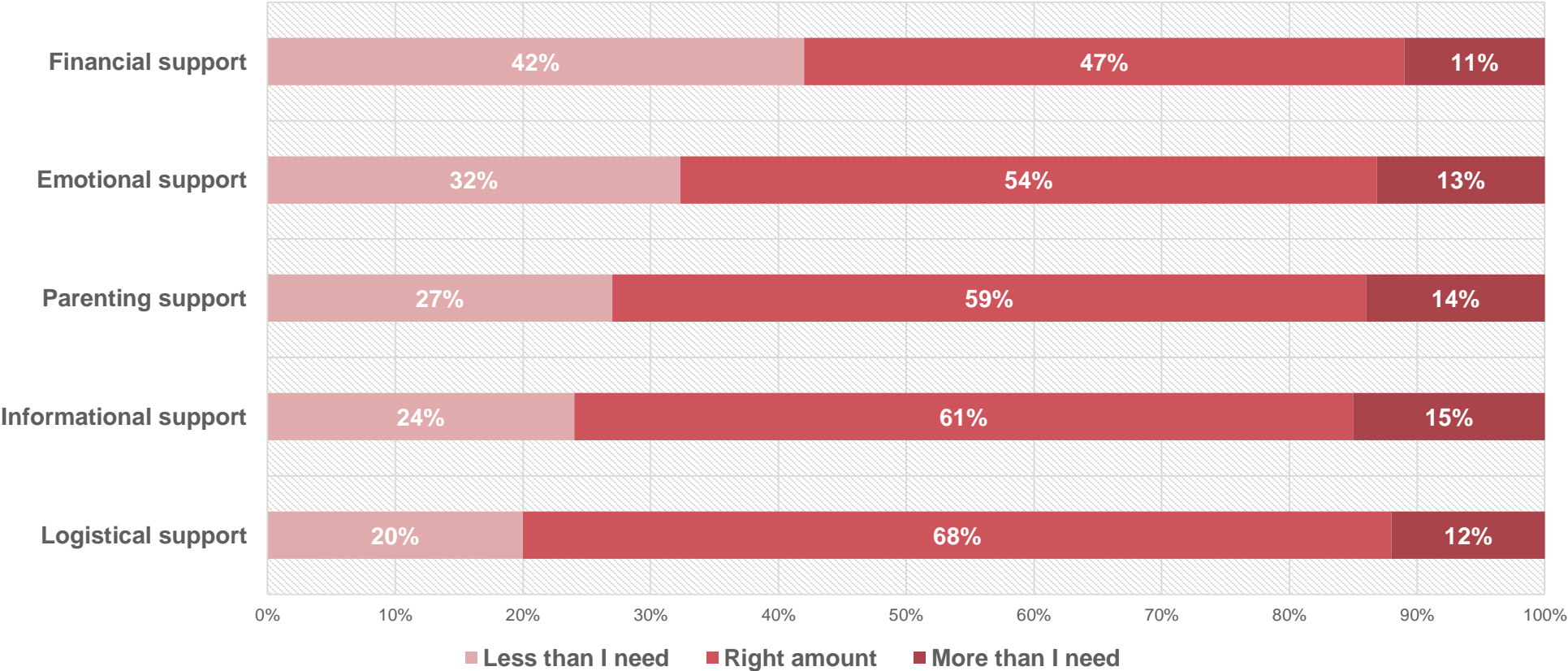





# CAREGIVER BURDEN AND SUPPORT

Parents spend an average of 20 hours per week on things related to their child’s treatment.

*As a caregiver, how much support do you have available to you?*



Moms are more likely than dads to say they are getting less support than they need in all areas except informational support.



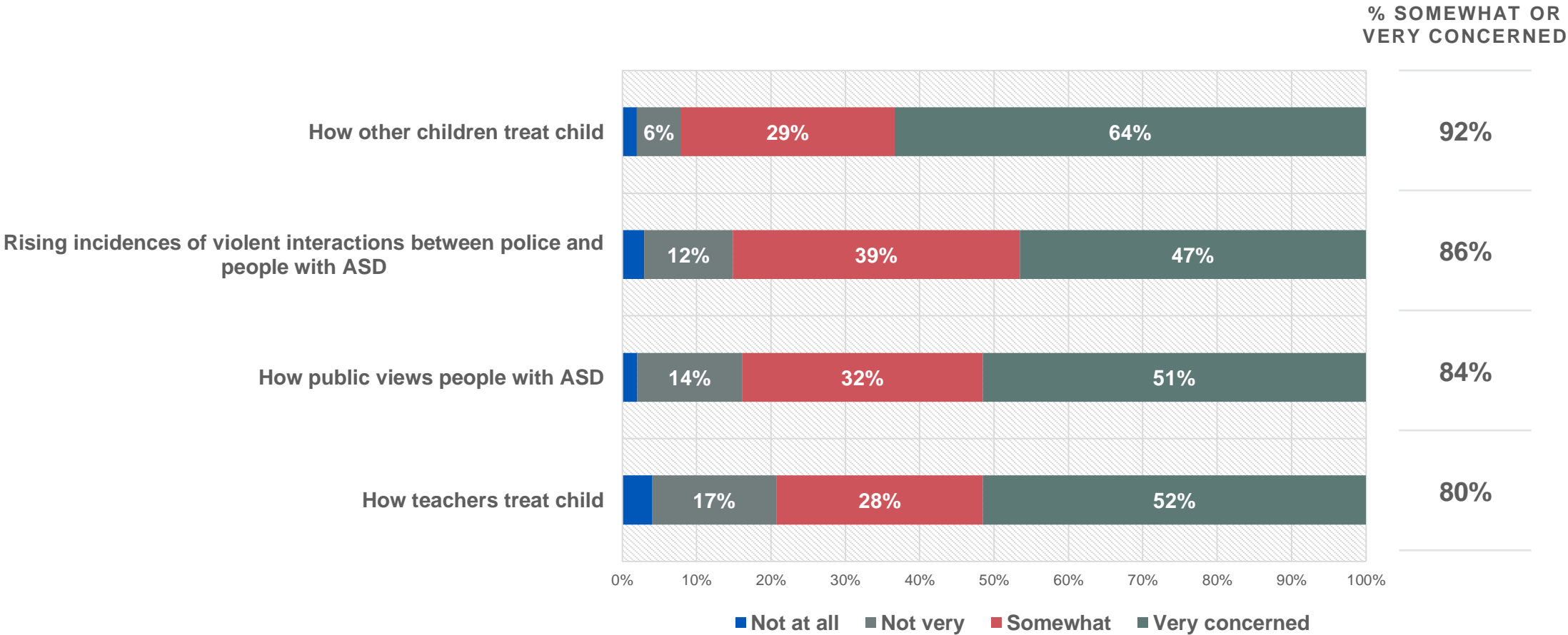
**86% of parents agree,  
“I wish there was a person I could turn  
to who would help me coordinate my  
child’s treatment and care.”**



# PARENT CONCERNS

Almost all parents are concerned about how other children treat their child.

Most are also concerned about the rising number of violent interactions between police and other authority figures and people with ASD.





# MEDIA & TECHNOLOGY



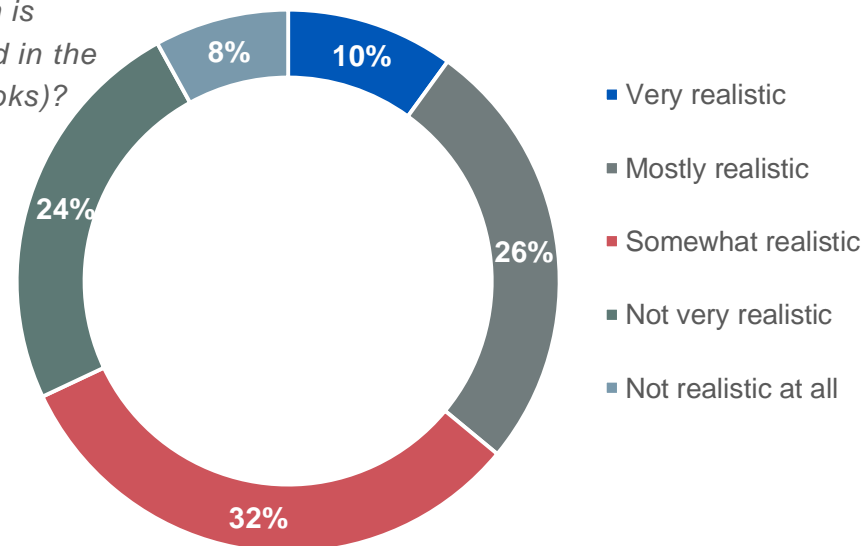


# MEDIA

64% of those surveyed said the media represents autism somewhat, not very or not at all realistically, showing room for improvement in the accurate portrayal and understanding of ASD in pop culture.

Several shows were mentioned as being good examples, however shows/movies, such as The Good Doctor and Rain Man, where characters also show savant behavior were disliked by some.

*How do you feel autism is represented or depicted in the media (movies, TV, books)?*

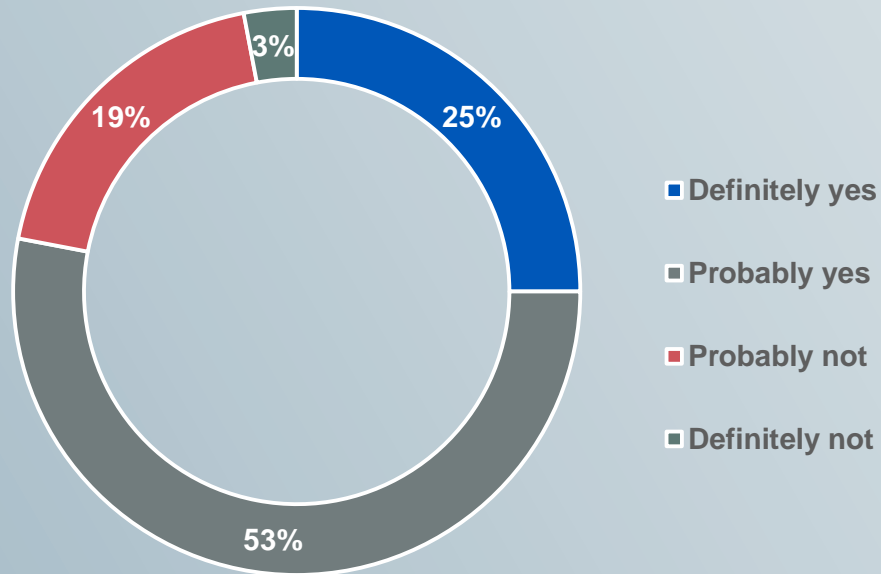


# TECHNOLOGY

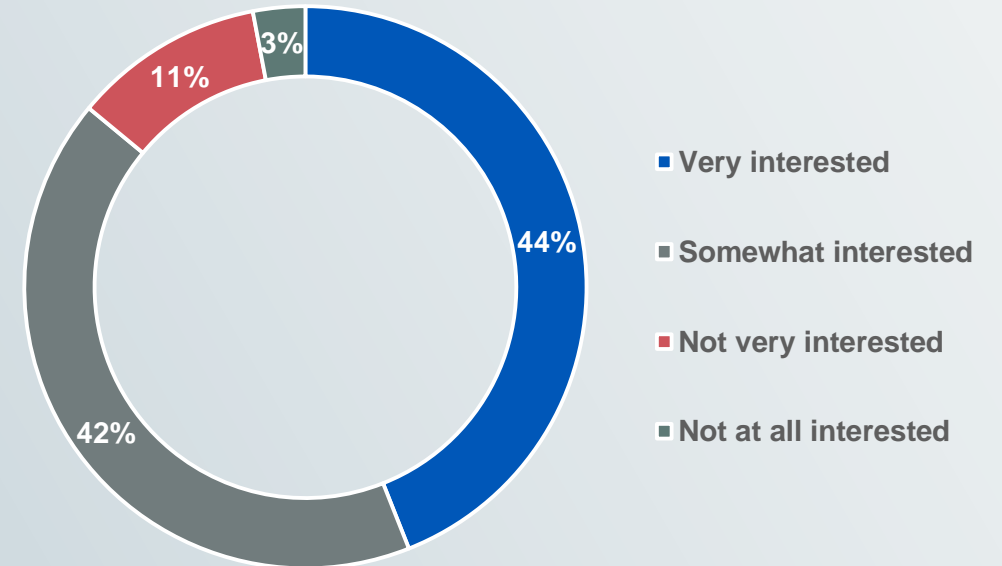
More than three-quarters of parents believe that home technology like Siri and Alexa could be used to help socialize children with autism.

**Most parents would be interested in a new virtual reality simulation that could lead to better outcomes between people with ASD and police or other authority figures.**

*Do you feel at-home voice activated smart speakers (like Siri and Alexa) could benefit autistic children with their socialization?*



*Interested in virtual reality simulation*





THANK YOU



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