

★  
**LEARNING  
HEROES**

# The Parent Journey: *Cracking the Code for Families of Children with Learning Differences*

Findings from a Study among K-12 Parents

MAY 2023

Supported by:



Research conducted by:



# Research Objectives

---



## IDENTIFYING THE ISSUES

What is the parent journey to identify and evaluate a child with learning differences?



## FINDING THE SUPPORTS

Who do parents turn to and trust for information and guidance?



## REVEALING NEW OPPORTUNITIES

Where are there untapped opportunities to improve, enhance, and expand support for families?



# Oak Foundation

---

## Our mission

Oak Foundation commits its resources to address issues of global, social and environmental concern, particularly those that have a major impact on the lives of the disadvantaged.



Global



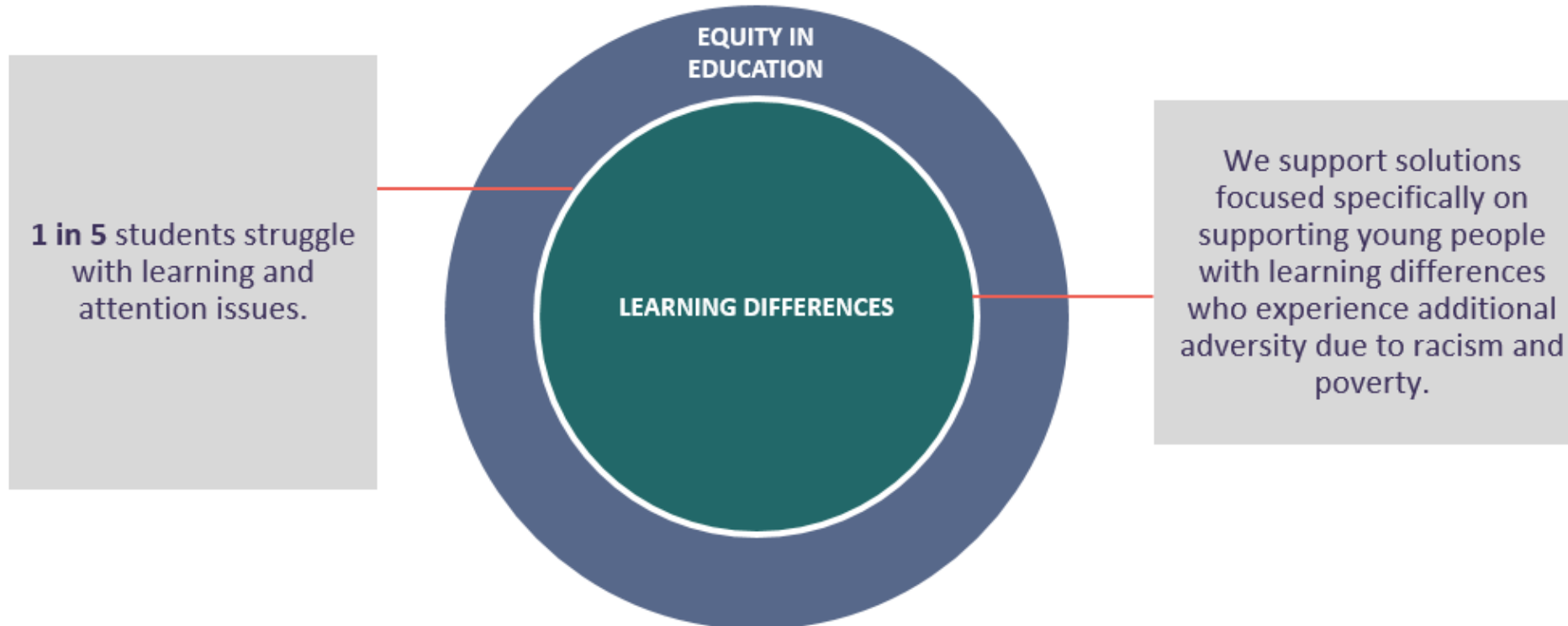
Social



Environmental

# Oak Foundation | Learning Differences Programme

Our work to support students with learning differences is grounded in a commitment to educational equity.



# Oak Foundation | “Learning Difference” Definition

**Study respondents have children who *have been diagnosed or children who they suspect* are experiencing one of the following conditions:**

- Dyslexia (difficulty reading)
- Dysgraphia (difficulty writing)
- Dyscalculia (difficulty in math)
- Executive Function Disorder
- ADD/ADHD (attention deficit hyperactivity disorder)
- Auditory and/or Visual Processing Disorders

# Iterative Research Process

---

**PHASE 1 | Landscape Scan, Expert Interviews**  
JUNE 2022

**PHASE 2 | In-depth Interviews**  
JULY & AUGUST 2022

**PHASE 3 | National Survey**  
OCTOBER & NOVEMBER 2022

**PHASE 4 | Follow-up Focus Groups**  
FEBRUARY & MARCH 2023

**PHASE 5 | Communications Playbook**  
MAY 2023



# Iterative Research Process

**Landscape Scan, Expert Interviews**  
JUNE 2022

**In-depth Interviews**  
JULY & AUGUST 2022

**National Survey**  
OCTOBER 2022

**Red Flag Focus Groups**  
FEBRUARY 2023



## Landscape Scan, Expert Interviews

- Summary of existing research and interviews with national experts to inform the research design:

**Mary Brownell**,  
distinguished professor of special education, University of Florida

**Shannon Garvey**,  
special education coach

**Jaime T. Koppel**, CEO,  
Communities for Just Schools Fund

**Lanya McKittrick**,  
senior research analyst, Center for Reinventing Public Education

**Brittney Newcomer**, associate director of thought leadership, Understood

**Robin Tatsuda**, CEO,  
ARC of King County, WA

**Jane West**, Jane West Consulting, specialist in education policy

JUNE 2022

# Iterative Research Process

**Landscape Scan, Expert Interviews**  
JUNE 2022

**In-depth Interviews**  
JULY & AUGUST 2022

**National Survey**  
OCTOBER 2022

**Red Flag Focus Groups**  
FEBRUARY 2023



## In-depth Interviews

- 15 Virtual IDIs among parents whose child has been diagnosed or experiencing a learning difference
- Mix of race/ethnicity, grade levels, geography, income (though majority of interviews among low-income families)

JULY & AUGUST 2022



# Iterative Research Process

**Landscape Scan, Expert Interviews**  
JUNE 2022

**In-depth Interviews**  
JULY & AUGUST 2022

**National Survey**  
OCTOBER 2022

**Red Flag Focus Groups**  
FEBRUARY 2023



## National Survey

- Online survey of parents of children who have been diagnosed or suspect their child has a learning difference (see definition)
- Oversamples of African American, Hispanic/Spanish-speaking, Asian American Pacific Islander (AAPI), and Indigenous descent parents
- Total N=2,845
- Survey in English & Spanish
- Key: % in *blue* stat higher, *red* lower

OCTOBER 2022

# Iterative Research Process

**Landscape Scan, Expert Interviews**  
JUNE 2022

**In-depth Interviews**  
JULY & AUGUST 2022

**National Survey**  
OCTOBER 2022

**Follow-up Focus Groups**  
MARCH 2023



## Follow-up Focus Groups

- 3 Focus Groups among a mix of parents whose child has been diagnosed or is experiencing at least one of the following:
- 1 group among AAPI parents, 1 group among Hispanic/Spanish-speaking parents, and 1 group among African American/Black parents
- Mix of grade levels, geography, income

MARCH 2023

# Cracking the Code | The First Steps



# How Can Parents “Crack the Code?”



## THE FIRST STEPS

Parents need support to confront barriers like fear and anxiety that can prevent them from identifying and accepting their child’s learning difference.



## EVALUATION & DIAGNOSIS

Early communication from trusted sources like pediatricians and teachers can lead to earlier intervention by parents.



## ACCESS TO SCHOOL SUPPORTS

Parents of students who are identified and receiving services are more satisfied than those who suspect their child has a learning difference.



## EFFECTIVE COMMUNICATIONS

More regular and comprehensive communication about services can help parents get the support their child needs.

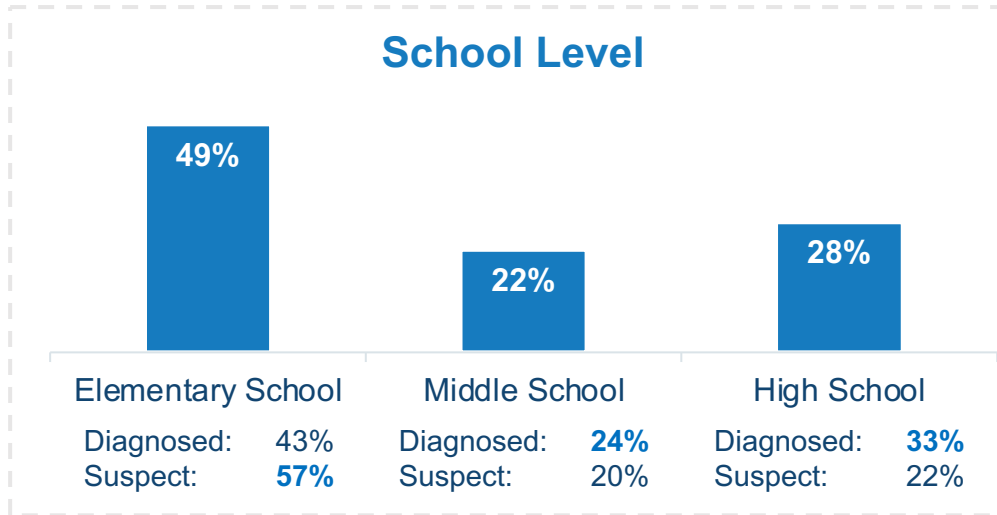
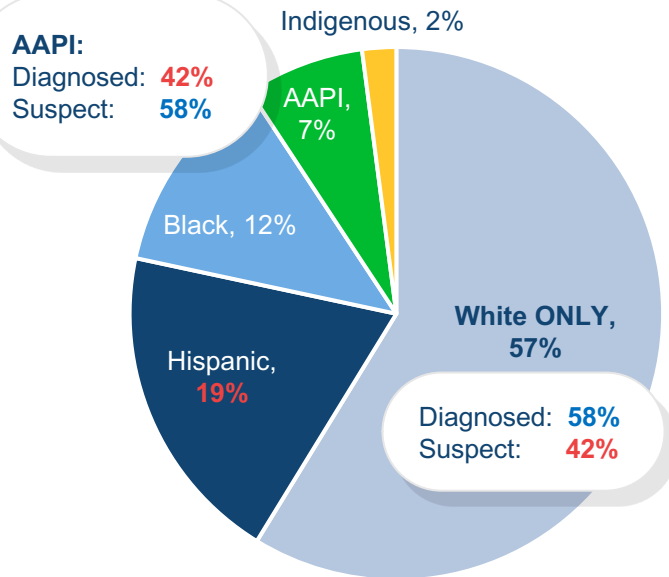
# Survey Respondent Profile | Learning Differences

	Diagnosed (54%)	Suspect (46%)	Total
ADD/ADHD	42%	33%	76%
Dyscalculia	8%	25%	32%
Dyslexia	12%	17%	29%
Dysgraphia	4%	13%	17%
Oppositional Defiance Disorder	7%	9%	16%
Auditory/Visual Processing Disorders	6%	8%	14%
Executive Function Disorder	3%	4%	7%
Anxiety <i>(not part of learning differences def)</i>	25%	33%	57%
Depression <i>(not part of learning differences def)</i>	13%	17%	30%

**Mental Health:**  
61% say Anxiety  
OR Depression,  
26% say both

**Average # of learning differences diagnosed and/or experienced: 1.76**

# Respondent Profile | Demographics



**52% have a Family Member with a Learning Difference**

Diagnosed **56%**

Suspect **46%**

Black 53%

Hispanic **46%**

AAPI **40%**

Indigenous 55%

White 54%

**58% Boy, 42% Girl**

Diagnosed: **63%** Diagnosed: 37%  
Suspect: 52% Suspect: **47%**

47% have an IEP or 504 Plan  
53% Do Not

44% are SNAP Eligible\*

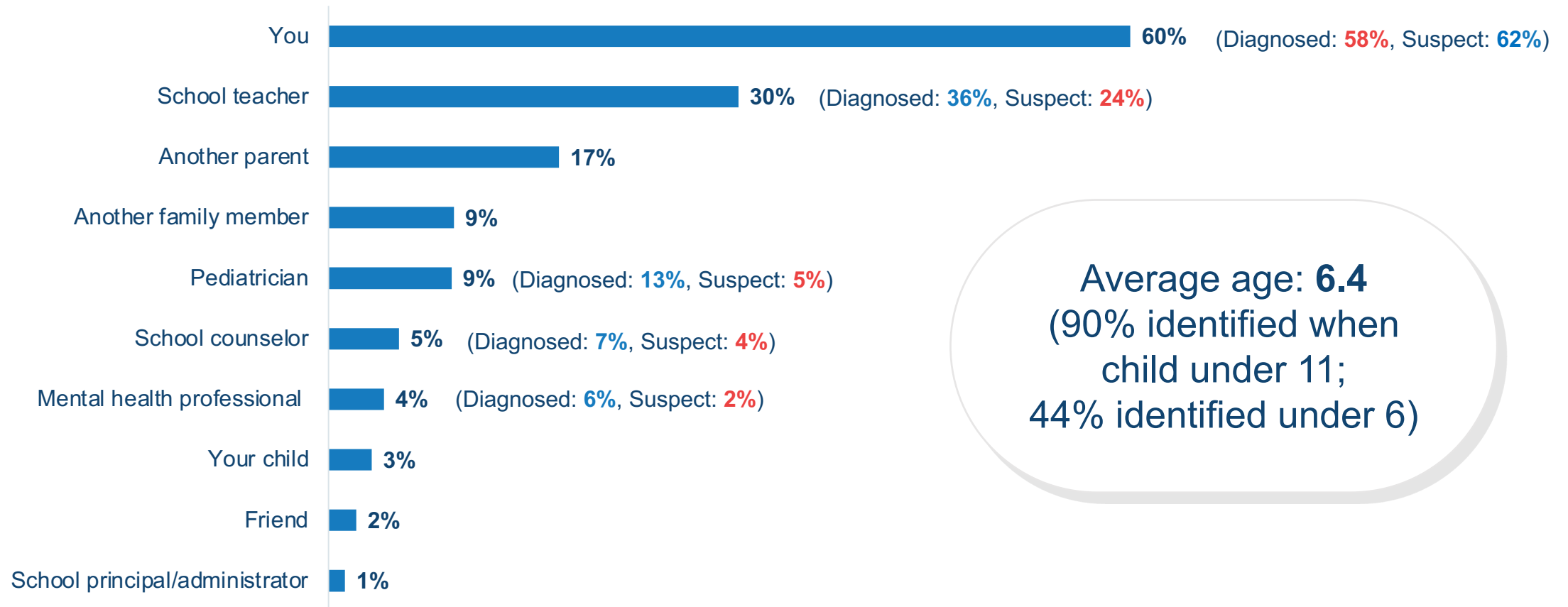
33% take Medication  
(**62%** ADD/ADHD diagnosis, 13% No ADD/ADHD)

\* Low-income households that are eligible for the Supplemental Nutrition Assistance Program (SNAP)



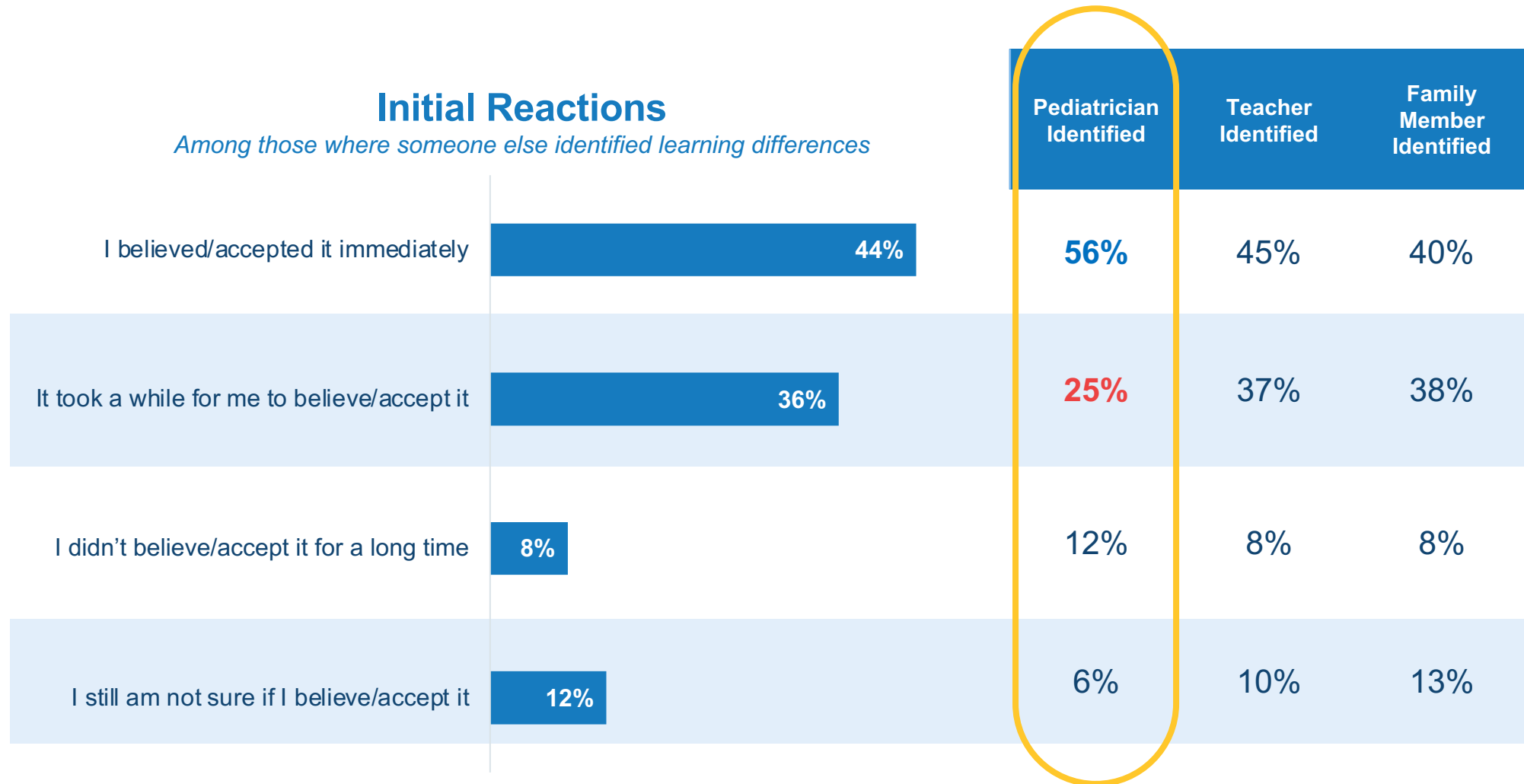
# Parents Most Likely to First Identify

Who first thought that your child may have a developmental and/or learning difference? (Select all that apply)



Average age: **6.4**  
(90% identified when  
child under 11;  
44% identified under 6)

# Acceptance | Split If Identification Wasn't the Parent



# Parent Experience | Feeling Judged

---

“When he first started school, I felt I was looked down on. I felt like I was judged. You’re a single mom, don’t have that much money ... I felt this tremendous sense of guilt, not that I did anything to cause it, but I felt guilty as a parent. I didn’t want him to have to struggle. I was lost and overwhelmed. The teachers are looking at me like, ‘Why can’t you control your child?’ I struggled a lot with that, being lost, confused, and guilty. I didn’t know how to fix it and help him.”

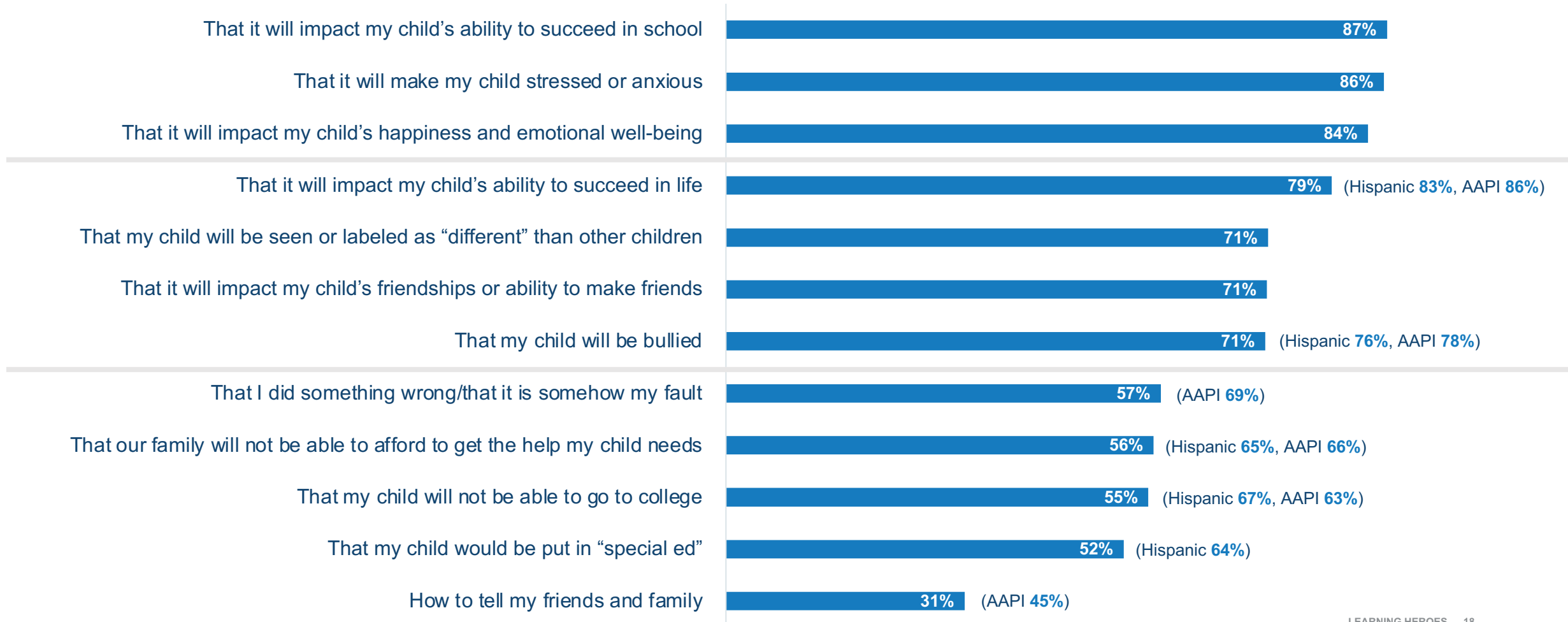
***(Parent from qualitative interviews)***



# Acceptance | Parents Are Anxious

When you first thought your child had a learning difference, how concerned were you about each of the following?

% Very/somewhat concerned



# Moms Describe Carrying the Burden

*In focus groups, mothers say they often have primary responsibility for navigating the system, advocating for their child, and providing emotional support. This can be exhausting and lonely.*

“It’s very difficult in my personal situation. It’s hard for my husband to accept certain things ... I have to fight harder. I’m the one who has to do a lot more things compared to my husband. And it’s not because he doesn’t want to, it’s that everything about this seems very difficult for him.”

– Hispanic Mother from focus groups

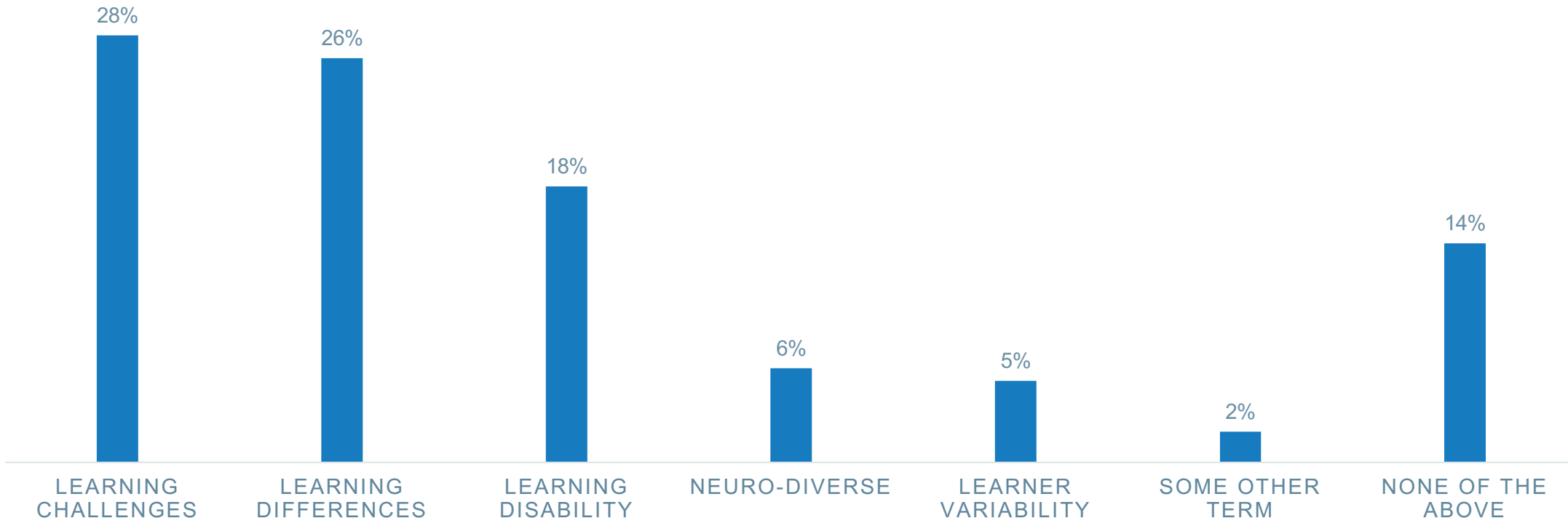
“[My support system is] my village, because... I have to still be a single mother and go to work. So, a friend will take him to his doctor’s appointment, his evaluations. It’s a lot of appointments... and patience... so my village is very helpful with him.”

– Black Mother from focus groups

# Which Term Resonates? It Depends...

As a parent, which one term do you prefer?

**Families who have a child with a diagnosis prefer “Learning Differences” or “Disability,” those without a diagnosis prefer “Learning Challenges”**





# Parents Are Concerned About Labels

*In focus groups, parents were concerned about deficit-based language that might make their child feel abnormal and impact their confidence. Many parents preferred using the official diagnosis (e.g., ADHD) or approach (e.g., IEP).*

28% prefer  
Learning  
Challenge

*“Challenge has never been positive when it comes to learning or education or mental ability. ‘Challenge’ has always had a negative connotation.” – Black Parent from focus groups*

6% prefer  
Neuro-  
diverse

*“I know the movement is to be politically correct, but ‘neuro,’ I don’t know. It’s almost too much for me.” – AAPI Parent from focus groups*

26% prefer  
Learning  
Difference

*“When you say ‘difference,’ it means you are not the norm... isolated to a particular group of people... It could be special different in a good way, or in a bad way. It depends.” – AAPI Parent from focus groups*

“Special ed”  
has negative  
connotations

*“It’s always associated with children with behavioral issues or physical disability. It’s another thing that has a negative connotation... so it’s a lot of history with that and it’s often used in a negative way or to disparage someone.” – Black Parent from focus groups*

18% prefer  
Learning  
Disability

*“The label ‘learning disability’ makes a child feel like they’re not capable. In the future, I would like a more positive label, something that’s more empowering.” – Hispanic Parent from focus groups*

Other terms  
used

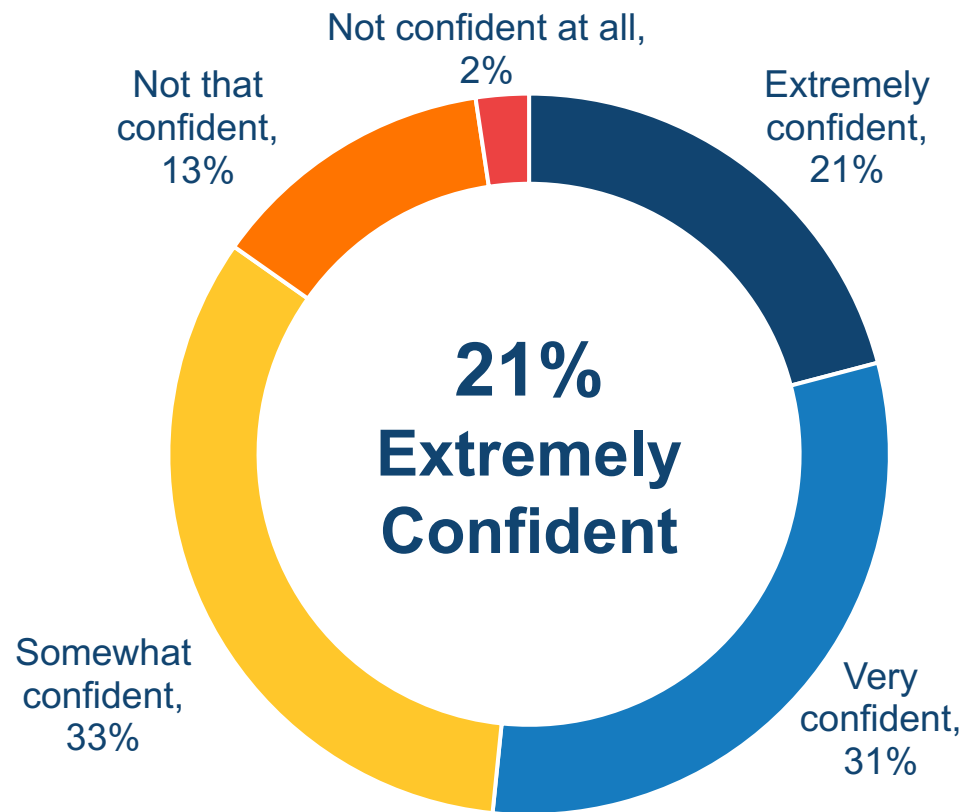
Official diagnosis or approach  
“ADHD,” “Dyslexia,” etc.  
“IEP”

# Cracking the Code | Evaluation & Diagnosis



# Just Half of Parents Confident About How to Help Their Child

How confident were you that you knew what do to get your child the help they needed for their developmental or learning difference?



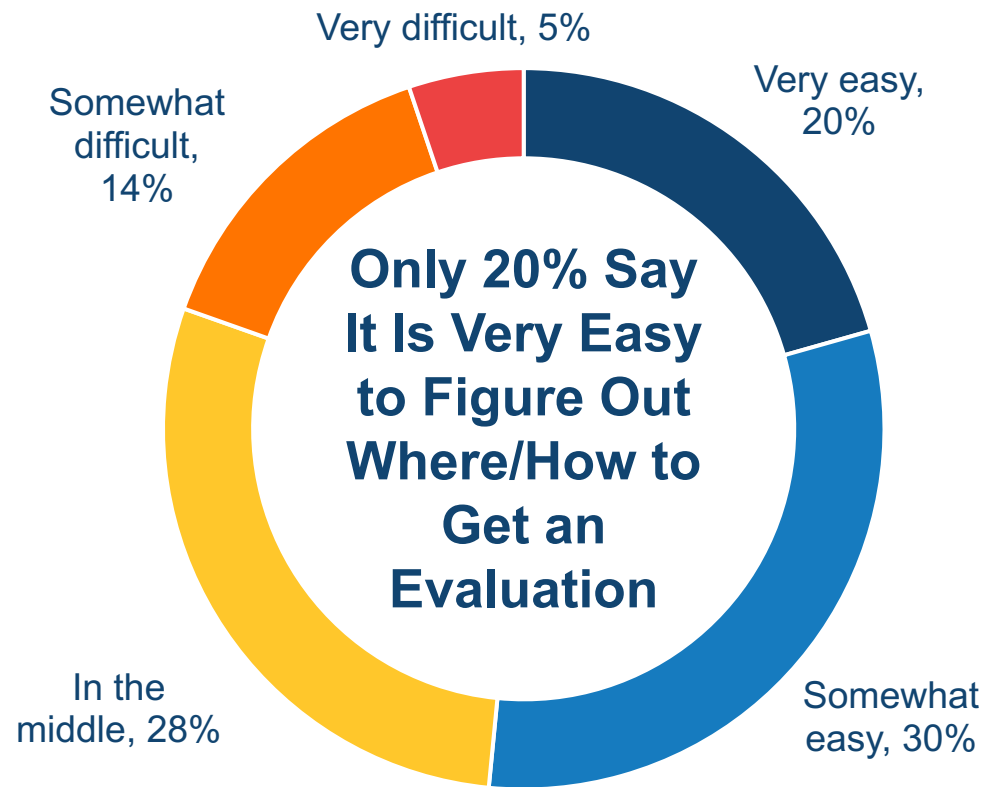
## % Extremely confident

Diagnosed: **26%**  
Suspect: **15%**

Black: **25%**  
Hispanic: 18%  
AAPI: **12%**  
Indigenous: 24%  
White: 21%

SNAP Eligible: **23%**  
Not SNAP Eligible: **19%**

# Evaluations | Few Find it Very Easy to Obtain



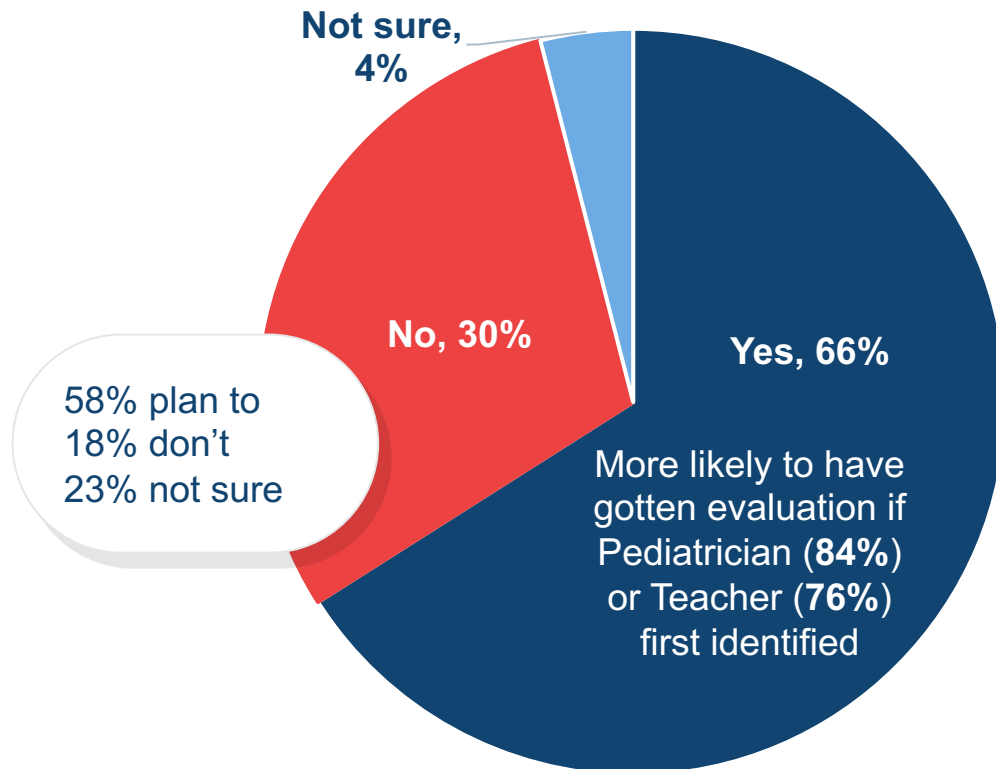
## % Very/Somewhat Easy

Diagnosed: **59%**  
Suspect: **40%**

Black: **52%**  
Hispanic: 46%  
AAPI: **38%**  
Indigenous: 48%  
White: **53%**

# Majorities Who Have Not Yet Gotten an Evaluation Have Waited 6 Months+

Has your child had an evaluation to determine a diagnosis of their developmental and/or learning difference?



## Top Barriers to Getting an Evaluation (among those who not planning or not sure)

Not sure my child has a learning difference and needs to be evaluated

My child will outgrow their behavior

Don't want my child to be labeled

My child just needs to try harder in school

Don't know where or how to get an evaluation

**73%** say it has been 6 months or more since someone first suspected  
(among those who plan to get an evaluation)

# Parent Experience | A Year Lost

---



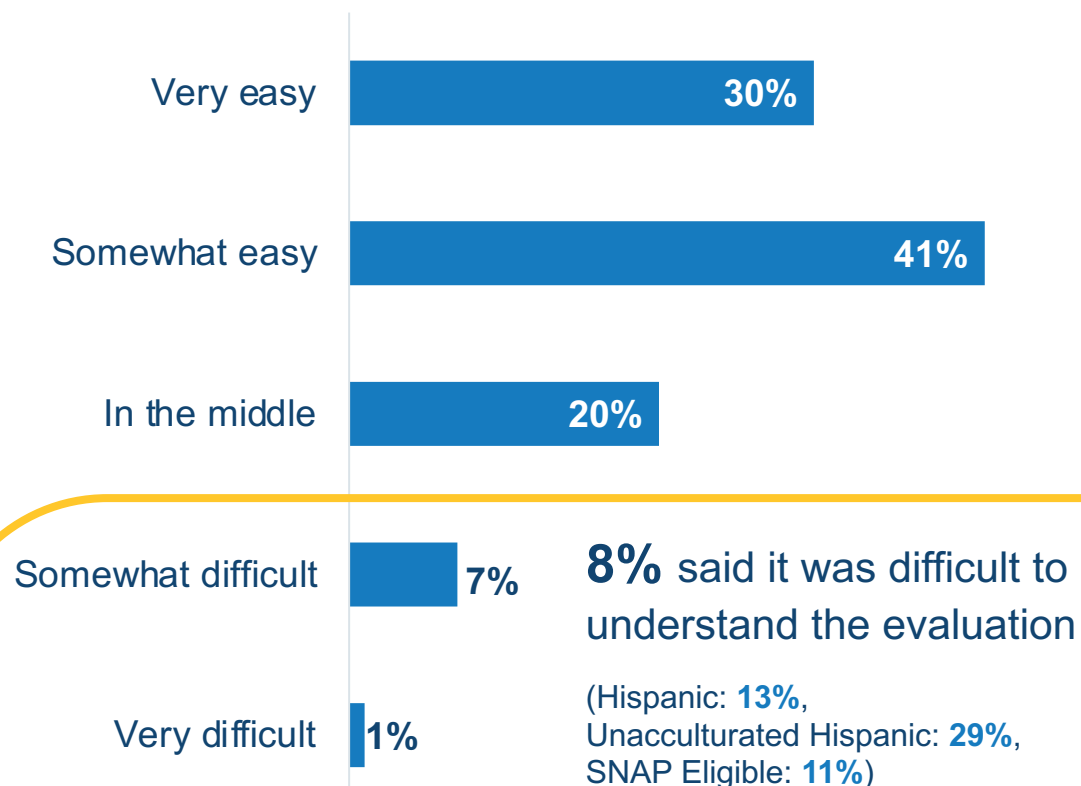
“If you’re going to let basically a whole year go by before saying we need to get her help...if I would have pushed the school a little bit more when they were saying hey there’s something wrong, maybe she would have been able to adapt to the medicine and get better grades earlier. I wish they would have suggested that she needed to be tested sooner.”

***(Parent from qualitative interviews)***



# Evaluation Experiences

How easy or difficult was it to understand the evaluation?  
(among those who had an evaluation)



No difference based on who conducted evaluation

What would have helped you better understand the evaluation?

*"Having someone explain it using **smaller words** or words that a normal person understands."*

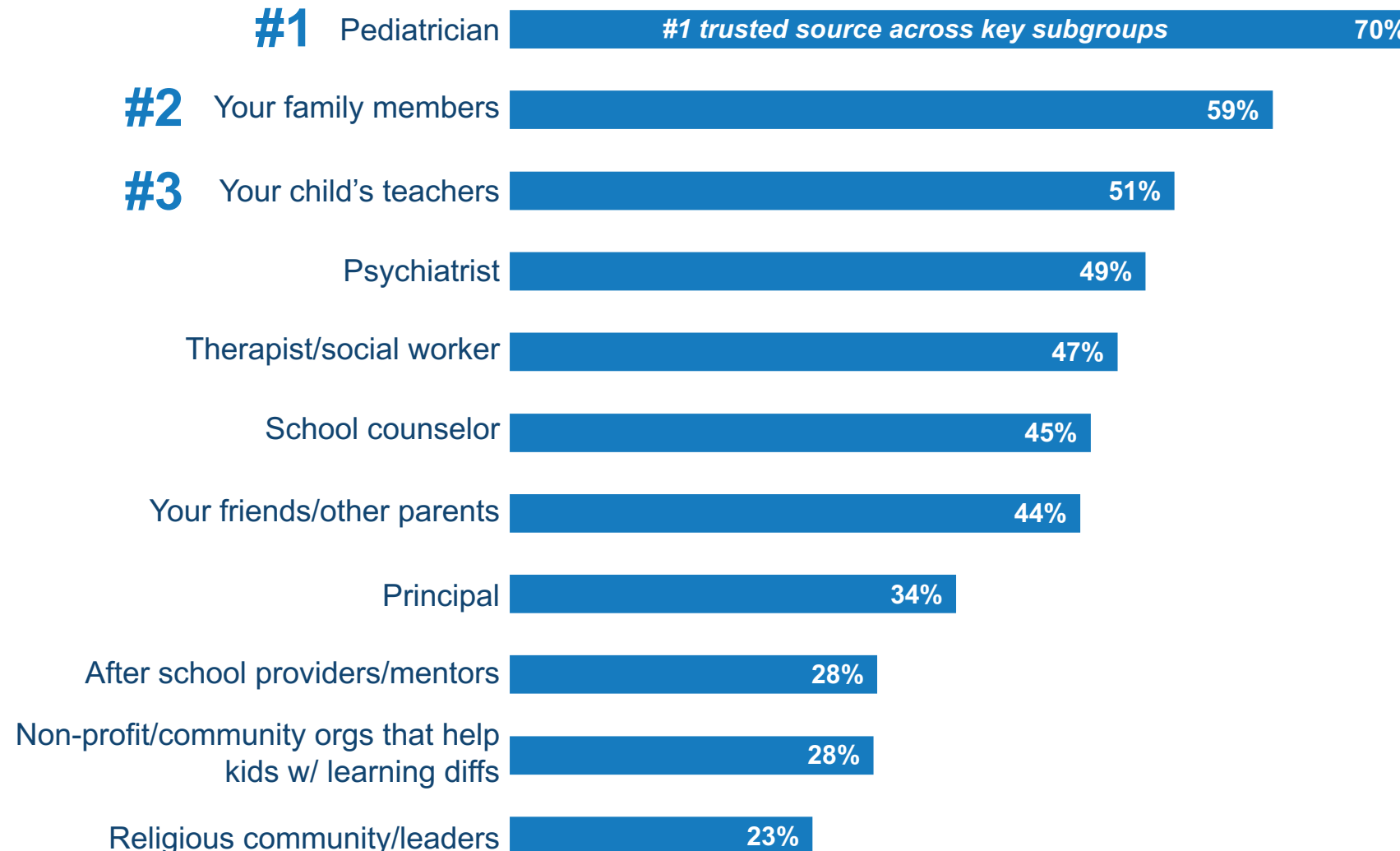
*"A parent version of the write up in **layman's terms**."*

*"If they would've explained it **instead of just handing me the test results**."*

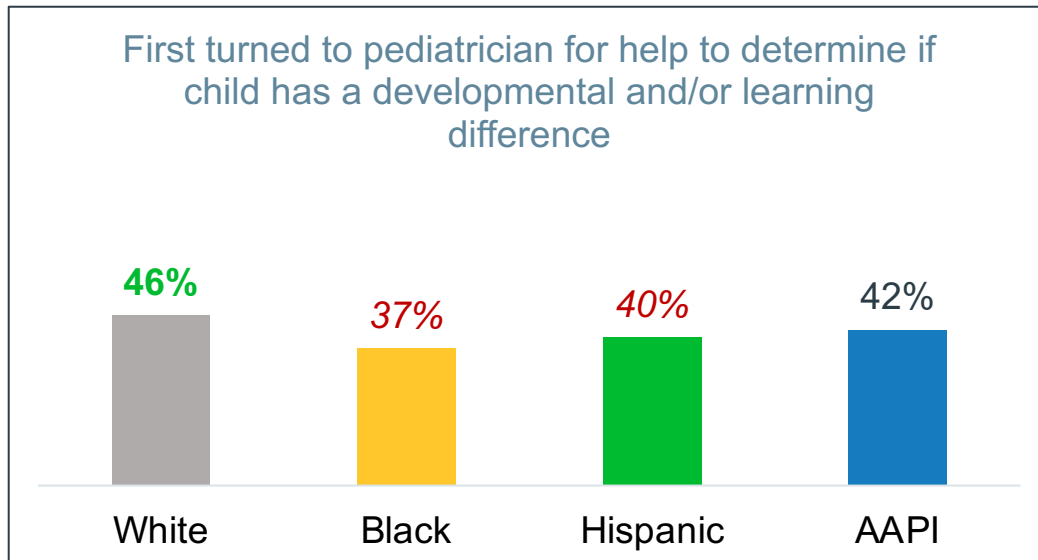
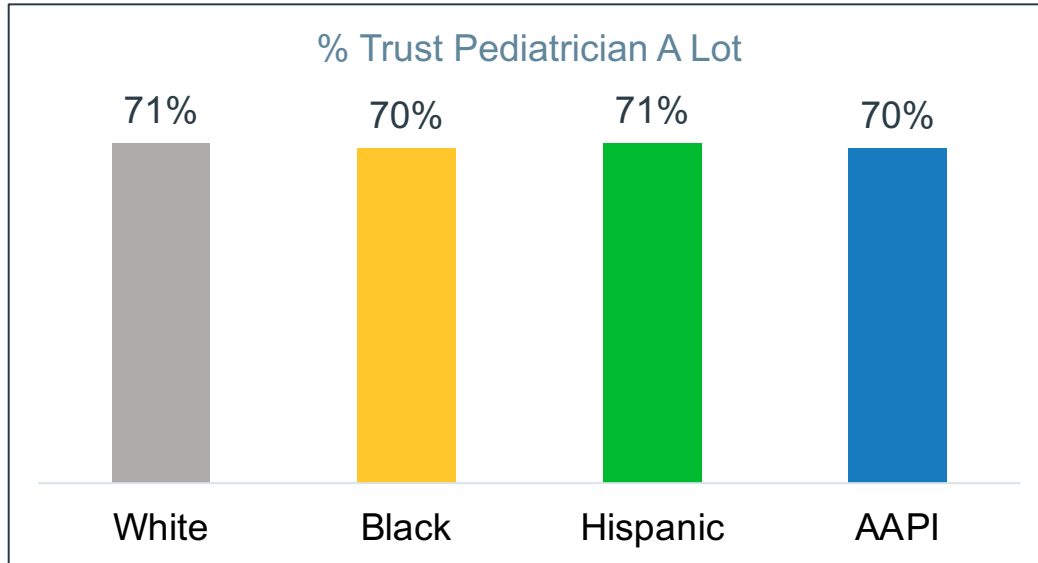
# Trusted Sources | Pediatricians Are the Lynchpin; Over Half Put their Trust in Teachers

How much do you trust the following people to help you and your child with their developmental or learning differences?

% Trust a lot



# Pediatricians #1 Source Across Racial/Ethnic Groups, But Differences Expressed in Focus Groups



## Focus Group Quotes...

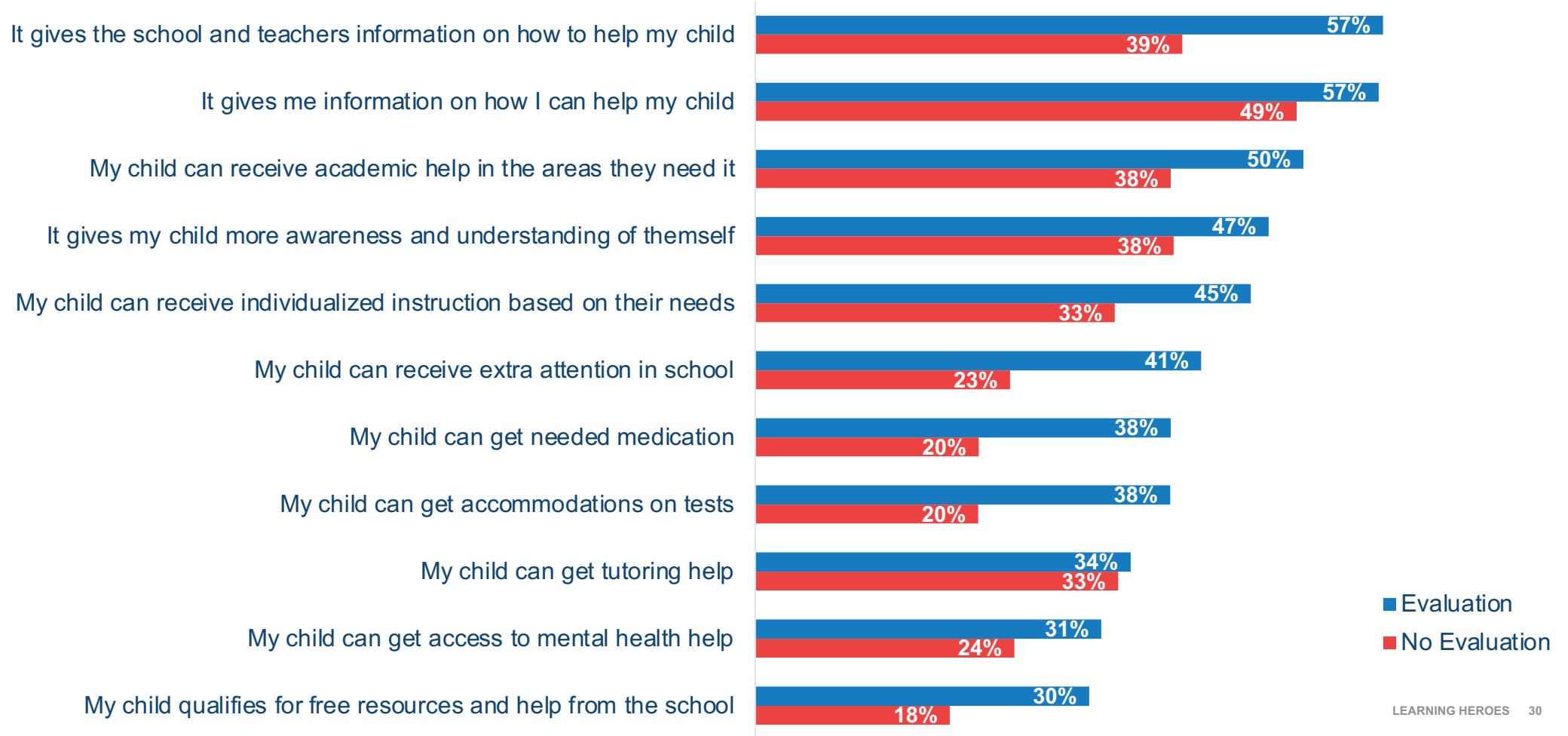
***“[I listen to] my son’s pediatrician all the time.”***  
– AAPI Parent from focus groups

***“Not the pediatrician regarding this topic. More general things, the cold or the flu, but for this, the guidance counselor has been excellent.”***  
– Hispanic Parent from focus groups

***“My pediatrician just pushes us to the specialists. ‘You need to go check that out over there’ or if I need to refill a prescription, [they] can’t help you with that. You’re going to have to go over there. My pediatrician is good for physicals and blood work.”*** – Black Parent from focus groups

# Better Communication Is Needed About How Schools Can Add Support with an Evaluation

In which of the following ways do you think having an evaluation can or has helped you and your child? Please select all that apply.



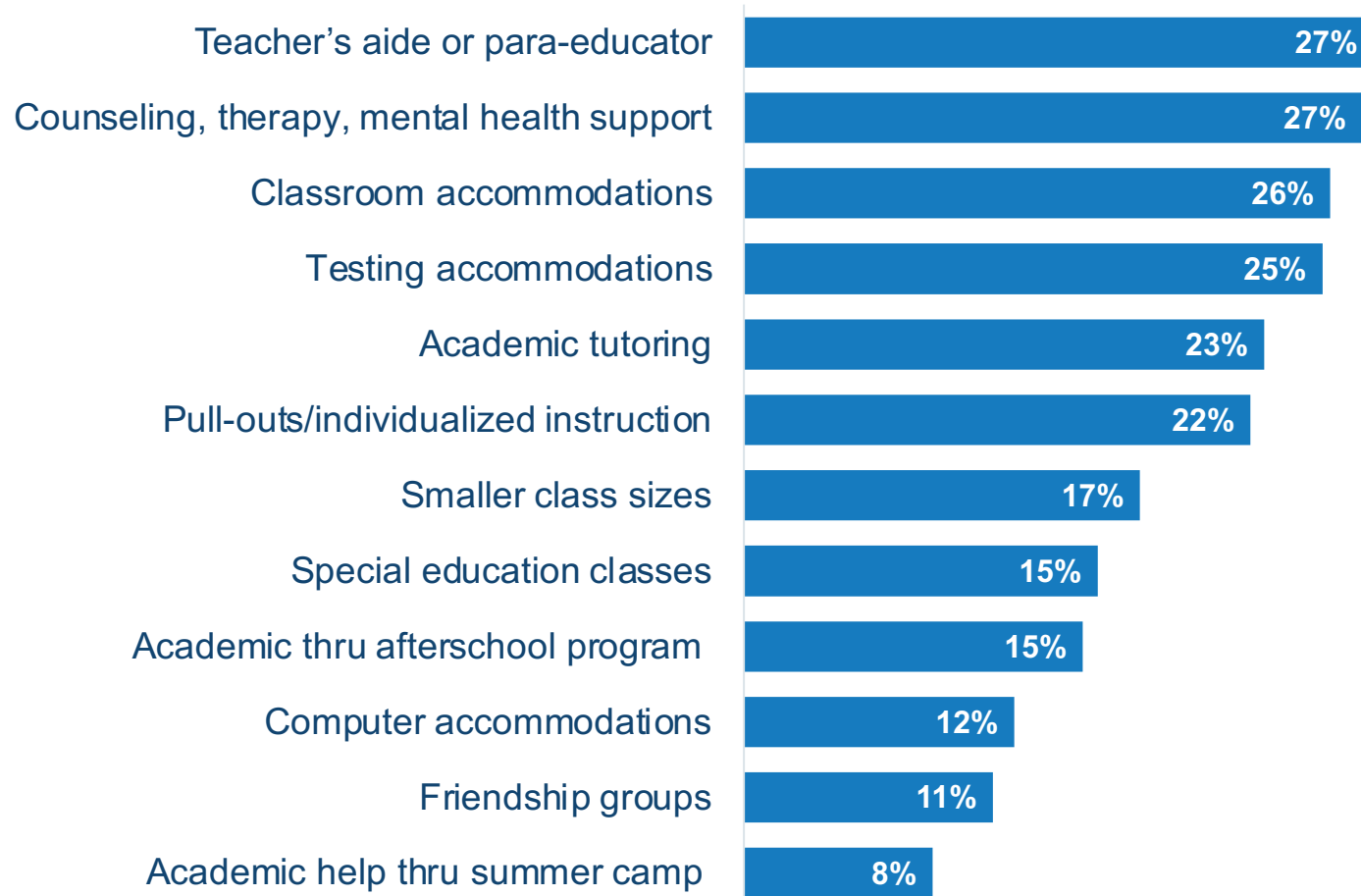
# Cracking the Code | Access to School Supports



# Most Parents Say Their Child Is Receiving Some Type of Service

Is your child receiving any of the following accommodations or services through school today?

(Please select all that apply)



**78% receive some type of service**

**Higher among:**

- Evaluation (**86%**)
- Urban (**83%**)
- Personal/family experience (**82%**)
- Boys (**80%**)
- SNAP Eligible (**80%**)
- No large racial or grade level differences
- **Younger diagnosed, more likely to have services**

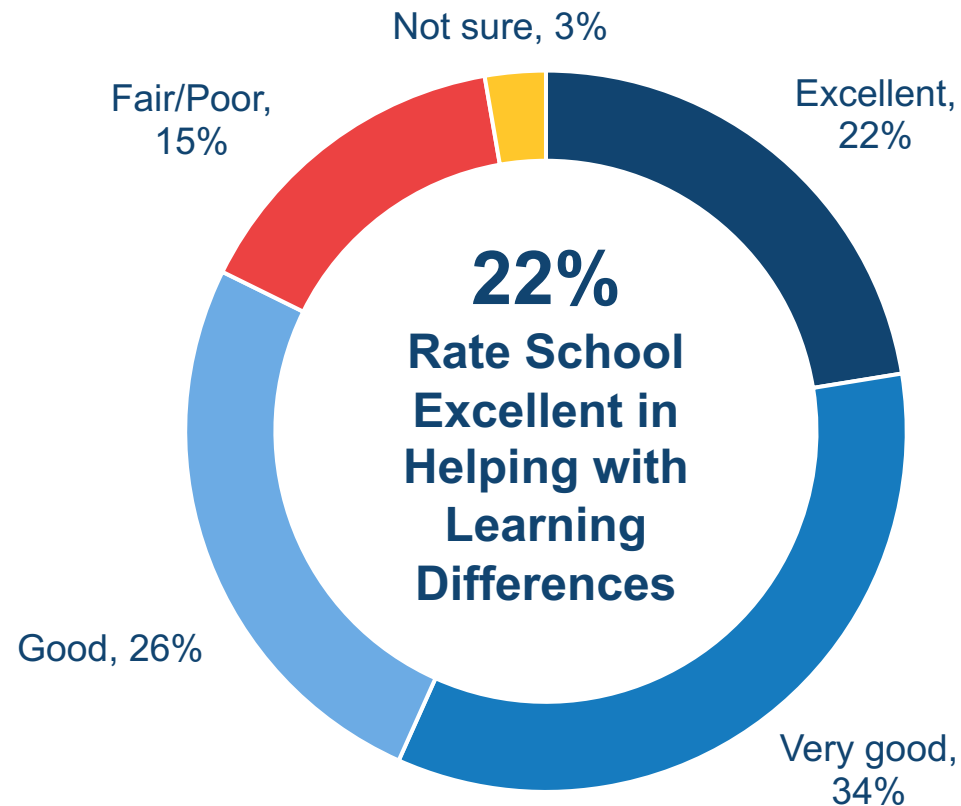
**The more services you receive,  
the happier you are with school**

Average # of services overall: 2.9  
Rate school as excellent: **3.6**



# Ratings of School Support Much Higher Among those Who Are Diagnosed vs. Suspect

How would you rate your child's school in helping you and your child with their developmental or learning differences?



% Excellent

Diagnosed: **27%**  
Suspect: **17%**

Black: 22%  
Hispanic: 26%  
AAPI: **13%**  
Indigenous: 23%  
White: 22%

SNAP Eligible: **25%**

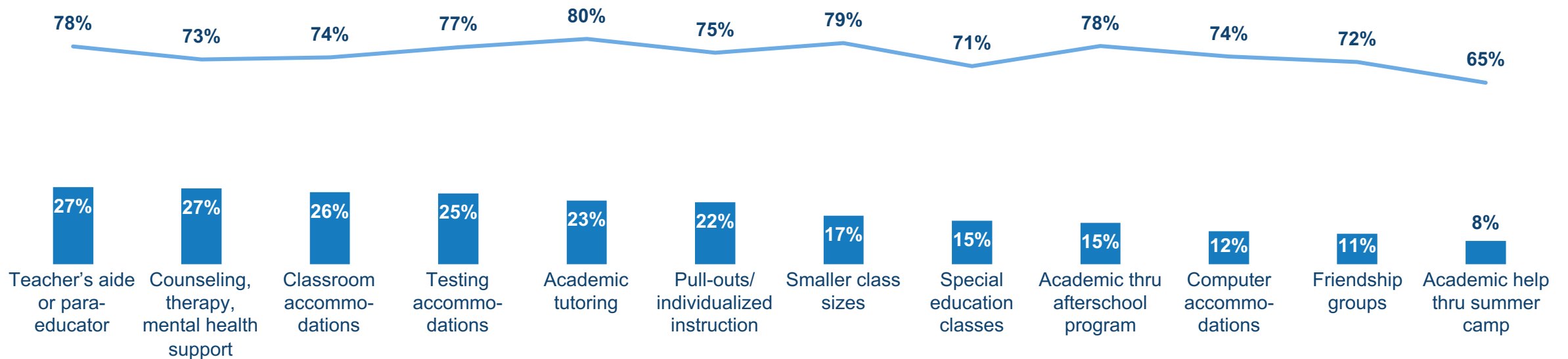
Elementary: **25%**  
Middle School: 21%  
High School: 20%

# More Services = More Satisfaction

Is your child receiving any of the following accommodations or services through school today? How helpful is each of the services your child receives through school with your child's developmental or learning difference?

(Among those who receive these services)

■ Receive — Very Helpful



37% 32% 33% 35% 28% 31% 21% 22% 19% 18% 16% 12%

Those who rate school as "excellent" are more likely to receive myriad services

# Half of Families Report Paying for Services Outside of School, on Average over \$2K Annually

48% pay for services outside of school

	SNAP Eligible	Not SNAP Eligible
Black	45%	59%
Hispanic	43%	65%
AAPI	44%	60%
Indigenous	38%	58%
White	40%	51%

SNAP Eligible	41%
Not SNAP Eligible	54%
Elementary	45%
Middle School	50%
High School	53%

Families spend \$227/month on average

Black	\$204
Hispanic	\$237
AAPI	\$252
Indigenous	\$261
White	\$227
SNAP Eligible	\$202
Not SNAP Eligible	\$239

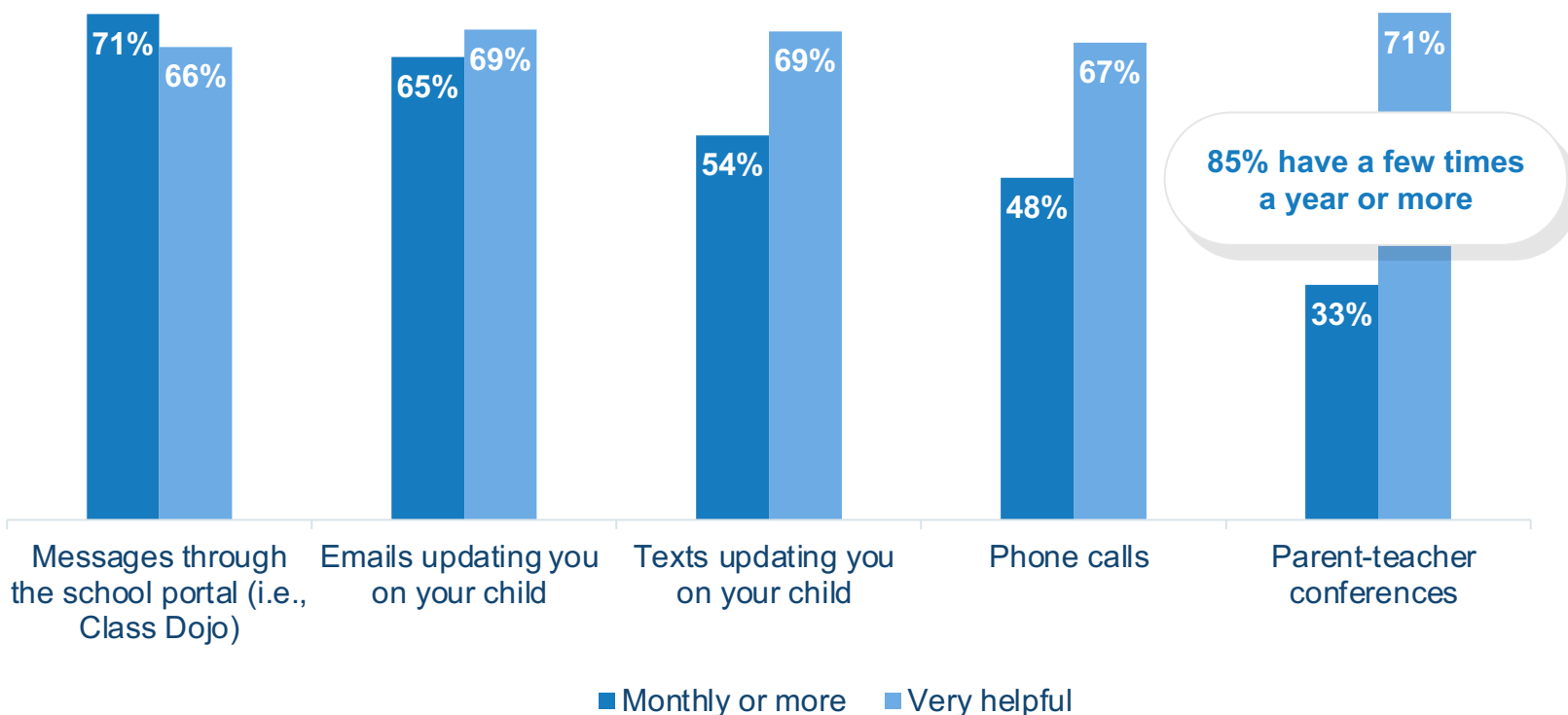
*Among those who pay for services*

# Cracking the Code | Effective Communications



# More Communication = Higher Ratings

## Regular School Communication + Helpfulness

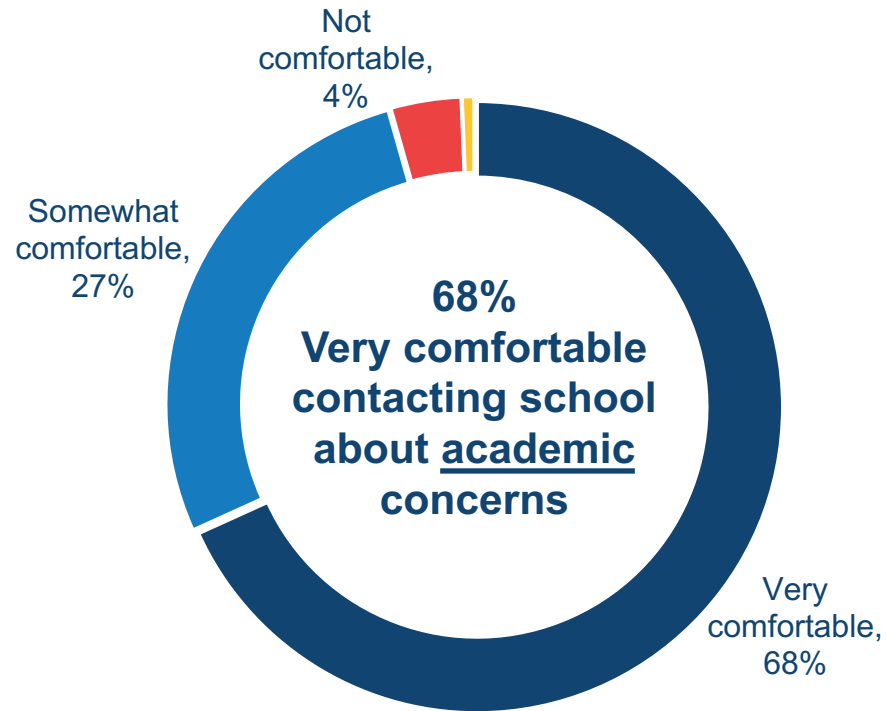


85% have a few times a year or more

Parents who say their school communicates at least monthly are twice as likely to rate their school as “excellent” in helping with learning differences

Para-Educators are key – parents communicating with them regularly are particularly happy

# Parents Are More Comfortable Discussing Academic vs. Social and Emotional Concerns

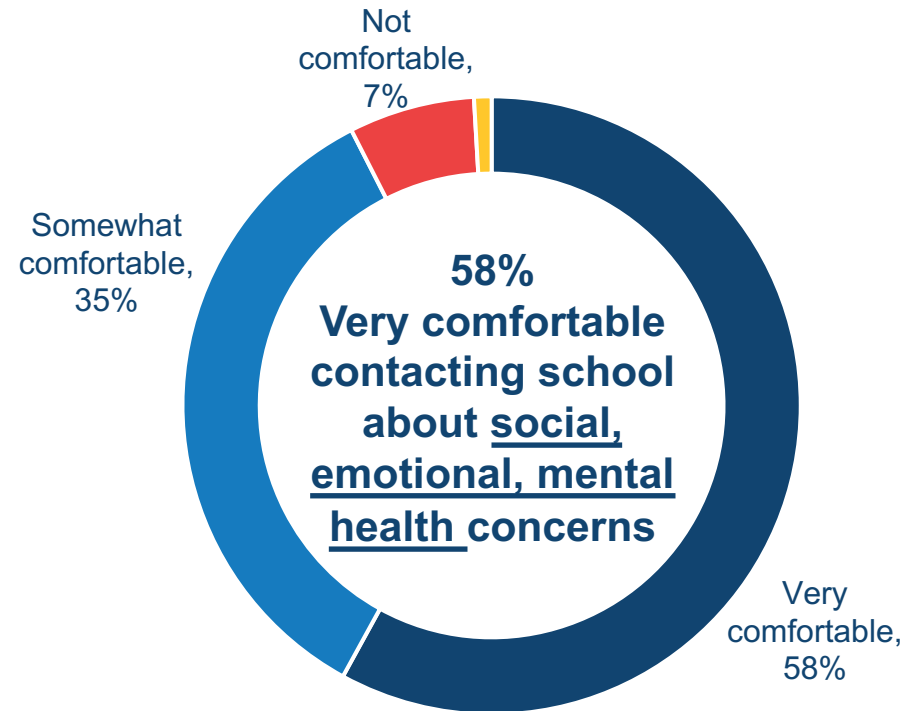


**Very comfortable higher among...**

Black: **74%**, Diagnosis: **71%**,  
Post Grad **74%**, Conservative **74%**

**Lower among...**

AAPI: **60%**, Suspect: **65%**



**Very comfortable higher among...**

Black: **68%**, Hispanic **61%**,  
Elementary **62%**, Diagnosis **60%**

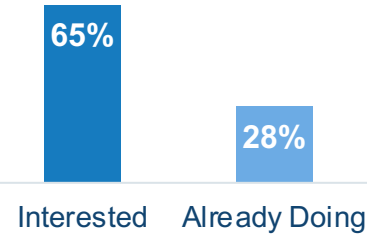
**Lower among...**

AAPI: **50%**, White **56%**, Suspect: **55%**

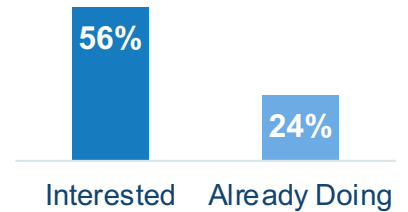
# Opportunities to Improve How Schools Can Help

Below are some different ways that parents might work with school to help with their child's developmental and/or learning differences. How interested are you in each?

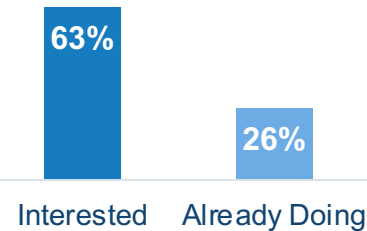
More information about **concrete ways** you can help your child at home



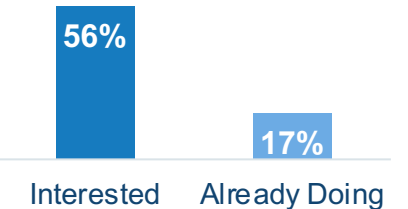
Connecting pediatrician and school to get a more **holistic approach** to child's needs



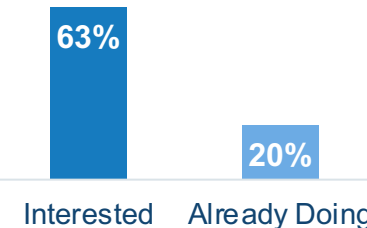
A **parent guide** on age-appropriate academic, social, and emotional milestones/indicators



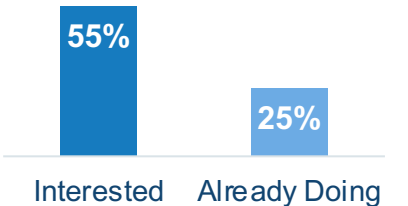
Participating in a **parent support group**



**Training program** for parents to better help and advocate for their child



Connecting mental health provider and school to get more **holistic approach**



Note: Gaps for all **significantly greater for those who suspect their child has a learning difference**





## Contact

**Bibb Hubbard**

Founder & President, Learning Heroes  
[bhubbard@learningheroes.org](mailto:bhubbard@learningheroes.org)

**Pam Loeb**

Principal, Edge Research  
[loeb@edgeresearch.com](mailto:loeb@edgeresearch.com)



Follow us on Instagram:  
[@learning.heroes](https://www.instagram.com/learning.heroes)



Follow us on LinkedIn:  
[@learning-heroes-us](https://www.linkedin.com/company/learning-heroes-us)



Like us on Facebook:  
[/Bealearninghero](https://www.facebook.com/Bealearninghero)



Follow us on Twitter:  
[@bealearninghero](https://twitter.com/bealearninghero)