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

Findings from a National Survey of K-12 Parents

FEBRUARY 2023
MISSION
Engage parents and caregivers as their children’s most effective advocate by ensuring they have a complete, holistic, and accurate picture of their children’s progress and success.

VISION
Parents and caregivers as learning heroes – advocating effectively for their children’s academic, social, and emotional success, driving equitable school improvement.
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.
Our work to support students with learning differences is grounded in a commitment to educational equity.

1 in 5 students struggle with learning and attention issues.

We support solutions focused specifically on supporting young people with learning differences who experience additional adversity due to racism and poverty.
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
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?
Research Phases

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 | Red Flag Focus Groups
FEBRUARY & MARCH 2023

PHASE 5 | Communications Playbook
APRIL 2023
Informed by Field Experts

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

☆ David Flink, founder and chief empowerment officer, EYETOEYE

☆ 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
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.
Cracking the Code | The First Steps
Phase 3 | 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

FIELDDED: OCTOBER 6-NOVEMBER 2, 2022
### Respondent Profile | Learning Differences

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

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

Average # of learning differences diagnosed and/or experienced: 1.76
Respondent Profile | Demographics

**Respondent Profile**

- **LEARNING HEROES**
- **Respondent Profile**

**Demographics**

- **White ONLY**: 57%
- **Hispanic**: 19%
- **Black**: 12%
- **Indigenous**: 2%
- **AAPI**: 7%

- **Diagnosed**: 52% have a Family Member with a Learning Difference
  - **Diagnosed**: 56%
  - **Suspect**: 46%

**School Level**

- **Elementary School**: 49%
- **Middle School**: 22%
- **High School**: 28%

**Respondent Profile**

- **Diagnosed**
  - **Elementary School**: 43%
  - **Middle School**: 24%
  - **High School**: 33%

- **Suspect**
  - **Elementary School**: 57%
  - **Middle School**: 20%
  - **High School**: 22%

**Respondent Profile**

- **58%** Boy, 42% Girl
  - **Diagnosed**: 63%
  - **Suspect**: 52%

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

**Respondent Profile**

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

**Respondent Profile**

- **44%** are SNAP Eligible*

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*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)

- You: 60% (Diagnosed: 58%, Suspect: 62%)
- School teacher: 30% (Diagnosed: 36%, Suspect: 24%)
- Another parent: 17%
- Another family member: 9%
- Pediatrician: 9% (Diagnosed: 13%, Suspect: 5%)
- School counselor: 5% (Diagnosed: 7%, Suspect: 4%)
- Mental health professional: 4% (Diagnosed: 6%, Suspect: 2%)
- Your child: 3%
- Friend: 2%
- School principal/administrator: 1%

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

*Among those where someone else identified learning differences*

<table>
<thead>
<tr>
<th>Reaction</th>
<th>Pediatrician Identified</th>
<th>Teacher Identified</th>
<th>Family Member Identified</th>
</tr>
</thead>
<tbody>
<tr>
<td>I believed/accepted it immediately</td>
<td>44%</td>
<td>56%</td>
<td>40%</td>
</tr>
<tr>
<td>It took a while for me to believe/accept it</td>
<td>36%</td>
<td>25%</td>
<td>38%</td>
</tr>
<tr>
<td>I didn’t believe/accept it for a long time</td>
<td>8%</td>
<td>12%</td>
<td>8%</td>
</tr>
<tr>
<td>I still am not sure if I believe/accept it</td>
<td>12%</td>
<td>6%</td>
<td>10%</td>
</tr>
</tbody>
</table>

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**Acceptance | Split If Identification Wasn’t the Parent**
“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?**

<table>
<thead>
<tr>
<th>Concern</th>
<th>Concerned %</th>
</tr>
</thead>
<tbody>
<tr>
<td>That it will impact my child’s ability to succeed in school</td>
<td>87%</td>
</tr>
<tr>
<td>That it will make my child stressed or anxious</td>
<td>86%</td>
</tr>
<tr>
<td>That it will impact my child’s happiness and emotional well-being</td>
<td>84%</td>
</tr>
<tr>
<td>That it will impact my child’s ability to succeed in life</td>
<td>79% (Hispanic 83%, AAPI 86%)</td>
</tr>
<tr>
<td>That my child will be seen or labeled as “different” than other children</td>
<td>71%</td>
</tr>
<tr>
<td>That it will impact my child’s friendships or ability to make friends</td>
<td>71%</td>
</tr>
<tr>
<td>That my child will be bullied</td>
<td>71% (Hispanic 76%, AAPI 78%)</td>
</tr>
<tr>
<td>That I did something wrong/that it is somehow my fault</td>
<td>57% (AAPI 69%)</td>
</tr>
<tr>
<td>That our family will not be able to afford to get the help my child needs</td>
<td>56% (Hispanic 65%, AAPI 66%)</td>
</tr>
<tr>
<td>That my child will not be able to go to college</td>
<td>55% (Hispanic 67%, AAPI 63%)</td>
</tr>
<tr>
<td>That my child would be put in “special ed”</td>
<td>52% (Hispanic 64%)</td>
</tr>
<tr>
<td>How to tell my friends and family</td>
<td>31% (AAPI 45%)</td>
</tr>
</tbody>
</table>
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”
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?

- 21% Extremely confident
- 21% Very confident
- 33% Somewhat confident
- 13% Not that confident
- 2% Not confident at all

% 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

Only 20% Say It Is Very Easy to Figure Out Where/How to Get an Evaluation

% Very/Somewhat Easy

- Diagnosed: 59%
- Suspect: 40%

By Race:
- 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?

- Yes, 66%
- No, 30%
- Not sure, 4%

More likely to have gotten evaluation if Pediatrician (84%) or Teacher (76%) first identified

58% plan to
18% don’t
23% not sure

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)
“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)

<table>
<thead>
<tr>
<th>Difficulty</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very easy</td>
<td>30%</td>
</tr>
<tr>
<td>Somewhat easy</td>
<td>41%</td>
</tr>
<tr>
<td>In the middle</td>
<td>20%</td>
</tr>
<tr>
<td>Somewhat difficult</td>
<td>7%</td>
</tr>
<tr>
<td>Very difficult</td>
<td>1%</td>
</tr>
</tbody>
</table>

8% said it was difficult to understand the evaluation:

- Hispanic: 13%
- Unacculturated Hispanic: 29%
- SNAP Eligible: 11%

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?

<table>
<thead>
<tr>
<th>Trusted Source</th>
<th>Trust a lot (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pediatrician</td>
<td>70%</td>
</tr>
<tr>
<td>Your family members</td>
<td>59%</td>
</tr>
<tr>
<td>Your child’s teachers</td>
<td>51%</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>49%</td>
</tr>
<tr>
<td>Therapist/social worker</td>
<td>47%</td>
</tr>
<tr>
<td>School counselor</td>
<td>45%</td>
</tr>
<tr>
<td>Your friends/other parents</td>
<td>44%</td>
</tr>
<tr>
<td>Principal</td>
<td>34%</td>
</tr>
<tr>
<td>After school providers/mentors</td>
<td>28%</td>
</tr>
<tr>
<td>Non-profit/community orgs that help kids w/ learning diffs</td>
<td>28%</td>
</tr>
<tr>
<td>Religious community/leaders</td>
<td>23%</td>
</tr>
</tbody>
</table>
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.

- It gives the school and teachers information on how to help my child: 57%
- It gives me information on how I can help my child: 57%
- My child can receive academic help in the areas they need it: 50%
- It gives my child more awareness and understanding of themself: 47%
- My child can receive individualized instruction based on their needs: 45%
- My child can receive extra attention in school: 41%
- My child can get needed medication: 38%
- My child can get accommodations on tests: 38%
- My child can get tutoring help: 34%
- My child can get access to mental health help: 31%
- My child qualifies for free resources and help from the school: 30%
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)

- Teacher’s aide or para-educator: 27%
- Counseling, therapy, mental health support: 27%
- Classroom accommodations: 26%
- Testing accommodations: 25%
- Academic tutoring: 23%
- Pull-outs/individualized instruction: 22%
- Smaller class sizes: 17%
- Special education classes: 15%
- Academic thru afterschool program: 15%
- Computer accommodations: 12%
- Friendship groups: 11%
- Academic help thru summer camp: 8%

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**: 22%
- **Very Good**: 34%
- **Good**: 26%
- **Fair/Poor**: 15%
- **Not sure**: 3%

22% Rate School Excellent in Helping with 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%
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

Teacher's aide or para-educator: 27% 78%
Counseling, therapy, mental health support: 27% 73%
Classroom accommodations: 26% 74%
Testing accommodations: 25% 77%
Academic tutoring: 23% 80%
Pull-outs/individualized instruction: 22% 75%
Smaller class sizes: 17% 79%
Special education classes: 15% 71%
Academic thru afterschool program: 15% 78%
Computer accommodations: 12% 74%
Friendship groups: 11% 72%
Academic help thru summer camp: 8% 65%

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

37% 32% 33% 35% 28% 31% 21% 22% 19% 18% 16% 12%
Half of Families Report Paying for Services Outside of School, on Average over $2K Annually

48% pay for services outside of school

<table>
<thead>
<tr>
<th>Race/Culture</th>
<th>SNAP Eligible</th>
<th>Not SNAP Eligible</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black</td>
<td>45%</td>
<td>59%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>43%</td>
<td>65%</td>
</tr>
<tr>
<td>AAPI</td>
<td>44%</td>
<td>60%</td>
</tr>
<tr>
<td>Indigenous</td>
<td>38%</td>
<td>58%</td>
</tr>
<tr>
<td>White</td>
<td>40%</td>
<td>51%</td>
</tr>
</tbody>
</table>

Families spend $227/month on average

<table>
<thead>
<tr>
<th>Race/Culture</th>
<th>SNAP Eligible</th>
<th>Not SNAP Eligible</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black</td>
<td>$204</td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>$237</td>
<td></td>
</tr>
<tr>
<td>AAPI</td>
<td>$252</td>
<td></td>
</tr>
<tr>
<td>Indigenous</td>
<td>$261</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>$227</td>
<td></td>
</tr>
</tbody>
</table>

Among those who pay for services
Cracking the Code | Effective Communications
More Communication = Higher Ratings

Regular School Communication + Helpfulness

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

- 68% Very comfortable contacting school about academic concerns
  - Very comfortable: 68%
  - Somewhat comfortable: 27%
  - Not comfortable: 4%
- 58% Very comfortable contacting school about social, emotional, mental health concerns
  - Very comfortable: 58%
  - Somewhat comfortable: 35%
  - Not comfortable: 7%

Very comfortable higher among...
- Black: 74%, Diagnosis: 71%, Post Grad 74%, Conservative 74%
- Very comfortable higher among...
- Black: 68%, Hispanic 61%, Elementary 62%, Diagnosis 60%

Lower among...
- AAPI: 60%, Suspect: 65%
- 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?

<table>
<thead>
<tr>
<th>Option</th>
<th>Interested</th>
<th>Already Doing</th>
</tr>
</thead>
<tbody>
<tr>
<td>More information about <strong>concrete ways</strong> you can help your child at home</td>
<td>65%</td>
<td>28%</td>
</tr>
<tr>
<td>A <strong>parent guide</strong> on age-appropriate academic, social, and emotional milestones/indicators</td>
<td>63%</td>
<td>26%</td>
</tr>
<tr>
<td><strong>Training program</strong> for parents to better help and advocate for their child</td>
<td>63%</td>
<td>20%</td>
</tr>
<tr>
<td>Connecting pediatrician and school to get a more <strong>holistic approach</strong> to child’s needs</td>
<td>56%</td>
<td>24%</td>
</tr>
<tr>
<td>Participating in a <strong>parent support group</strong></td>
<td>56%</td>
<td>17%</td>
</tr>
<tr>
<td>Connecting mental health provider and school to get more <strong>holistic approach</strong></td>
<td>55%</td>
<td>25%</td>
</tr>
</tbody>
</table>

*Note: Gaps for all **significantly greater for those who suspect** their child has a learning difference*
What’s Next?
Next Steps

3 Focus Groups | March
• Deep dive into families who have “cracked the code” and families who still suspect and have yet to obtain a diagnosis

Communications Playbook | April
• Suggestions? Contact us at Playbook@LearningHeroes.org
Contact

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