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Six Stages of Engagement in ADHD Treatment Described by Diverse, Urban Parents

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Abstract

BACKGROUND: Attention-deficit/hyperactivity disorder (ADHD) is a common neurodevelopmental condition in children. Although ADHD is treatable, barriers remain to engagement in treatment, especially among socioeconomically disadvantaged and racial and ethnic minority families. Our goal was to examine the process by which families engage in ADHD treatment and to identify targets for an intervention to improve engagement in care.

METHODS: We conducted in-depth semistructured qualitative interviews with 41 parents of diverse youth aged 3 to 17 years old in treatment of ADHD at an urban safety net hospital. Parents were asked about their journey through diagnosis and treatment, community attitudes about ADHD, and other factors influencing treatment access and decision-making. Transcripts were analyzed by using thematic analysis.

RESULTS: Of children with ADHD, 69.2% were male, 57.7% were Black or African American, and 38.5% were of Hispanic, Latino, or Spanish origin. Parents were 92.7% female, were 75.6% English speaking, and had a median income of \$20 000. Parents described 6 stages to the process of engaging in care for their child's ADHD, which unfolded like a developmental process: (1) normalization and hesitation, (2) fear and stigmatization, (3) action and advocacy,

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Dr Spencer conceptualized and designed the study, developed the data collection instruments, coordinated and supervised data collection, conducted the thematic analysis, drafted the initial manuscript, and reviewed and revised the manuscript; Ms Sikov, Ms Loubeau, and Ms Zolli recruited participants and collected data, conducted the thematic analysis, drafted the initial manuscript, and reviewed and revised the manuscript; Ms Baul developed data collection instruments, supervised and conducted the thematic analysis, drafted the initial manuscript, and reviewed and revised the manuscript; Ms Rabin, Ms Hasan, Ms Rosen, and Ms Buonocore collected data, conducted the thematic analysis, and reviewed and revised the manuscript; Ms Lejeune and Mr Dayal drafted the initial manuscript and reviewed and revised the manuscript; Drs Fortuna, Borba, and Silverstein conceptualized and designed the study, guided the process of the thematic analysis, and critically reviewed the manuscript for important intellectual content; and all authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

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(4) communication and navigation, (5) care and validation, and (6) preparation and transition. Barriers often occurred at points of stage mismatch between parents and providers and/or systems. Difficulty resolving an earlier stage interfered with the progression through subsequent stages.

CONCLUSIONS: The 6 stages framework could be used to develop new strategies to measure engagement and to design family-centered interventions to facilitate engagement in ADHD treatment.

Attention-deficit/hyperactivity disorder (ADHD) is one of the most common pediatric health conditions, affecting between 8% and 12% of school-aged children.^{1,2} ADHD is associated with significant dysfunction,³⁻⁷ and its burden can be particularly devastating for socioeconomically disadvantaged and racial and ethnic minority children, who already face high rates of educational underachievement, overrepresentation in the justice system, and low economic mobility.⁸⁻¹⁰

Although there are many treatment options for ADHD that improve lifelong outcomes,¹¹⁻¹⁸ treatment use and adherence, often collectively referred to as engagement in care,¹⁹ remains low in certain populations and not optimized for many patients.²⁰⁻²⁵ Engagement in ADHD treatment is particularly challenging for low-income and racial and ethnic minority families, who have less service use, higher treatment dropout, and greater loss to follow-up than other families.²⁶⁻³² Yet there are few studies that examine the process by which families engage in treatment^{33,34} and few well-tested interventions to improve engagement in ADHD care.

We conducted in-depth interviews with diverse, urban parents whose children were in treatment for ADHD at our safety net hospital to understand how these families came to engage in treatment for their children. We used qualitative methods to explore how and why families are delayed or deterred from seeking treatment from their perspective and to identify possible targets for a family-centered intervention to facilitate engagement in ADHD care.

METHODS

Setting and Participants

Legal guardians of children aged 3 to 17 years old in treatment of ADHD were recruited by clinician referral and waiting room advertisements from pediatric clinics at Boston Medical Center (BMC) between June 2018 and October 2019. BMC is the largest safety net hospital in New England, serving predominantly low-income and racial and ethnic minority patients from diverse cultural backgrounds. We recruited diverse families (English, Spanish, or Haitian Creole speaking) from a variety of pediatric treatment settings at BMC to increase the variability of perspectives. Participants were excluded if their child had comorbid autism, psychosis, or intellectual disability because these conditions would change the treatment focus. Potential participants were phone screened for eligibility and scheduled for an in-person study visit.

Data Collection Procedures

The study was approved by the Boston University Medical Campus Institutional Review Board. Written informed consent was obtained from parents by a research team member. Single semistructured in-depth interviews lasting 45 to 60 minutes were conducted alone with participants (without their children) by trained research staff who were fluent in the parent's preferred language. The interview guide (Supplemental Information) included open-ended questions to explore the journey of ADHD diagnosis and treatment, community attitudes about ADHD, and other factors influencing treatment access and decision-making. We used interview data to adapt questions and prompts iteratively. After the interview, parents completed a quantitative questionnaire, based on items from the National Survey of Children's Health³⁵ and the Child Behavior Checklist,³⁶ collecting sociodemographic and treatment information to measure child psychiatric symptoms. Interviews were conducted until theoretical saturation was reached.

Data Analysis

Interviews were audio recorded, transcribed verbatim, translated to English if applicable, and reviewed for accuracy. Transcripts were analyzed using thematic analysis³⁷ to identify patterns across participants through data familiarization, coding, and development of themes (broader shared meaning across participants). The first 5 transcripts were reviewed independently by 3 authors each and then discussed by the research team (AES, JS, JKL, NZ, TB, MR, SH, KR, OB) to develop an initial codebook. Interviews were then selected, in random order, to each be coded by 2 of 3 authors (NZ, JKL, JS) independently and discussed to resolve discrepancies and revise the codebook, including adding new codes. After 2 authors (NZ and JS) reached an intercoder reliability (Cohen's k) of 81% (exceeding our predetermined 75% threshold³⁸), the remaining interviews were each coded by 1 of 2 authors, double-coding after every 5 interviews to check that intercoder reliability was maintained. The research team (AES, JS, JKL, NZ, TB, MR, SH, KR) then met to discuss the relationships between themes and patterns in the data through axial coding.³⁹ We used NVivo 11 software⁴⁰ for data management.

RESULTS

Sample Characteristics

Of 130 potential participants screened, 26 were ineligible, 63 declined or could not be reached for their study visit, and 41 consented and completed interviews in English ($n = 31$; 75.6%), Spanish ($n = 9$; 21.9%), and Haitian Creole ($n = 1$; 2.4%). Parents were 92.7% female and had a mean age of 40.8 years ($SD = 7.6$). English was the primary language spoken at home for most participants (75%), but 41.8% were born outside the mainland United States, including in Puerto Rico (23.5%), Mexico (17.7%), and 7 other countries. Approximately half of the parents (51.8%) had received some postsecondary education, and the median income was \$20 000 (Table 1).

Children with ADHD ranged in age from 3 to 17 years (mean age 11; $SD = 3.3$); 69.2% were male, 57.7% were Black or African American, 38.5% were of Hispanic, Latino, or Spanish origin, and 80.5% were publicly insured. The majority had comorbid psychiatric

and/or learning disabilities, and more than half had asthma (68.8%). Almost all children had a lifetime history of receiving medication (97.6%), behavioral therapy (87.7%), and school accommodations (90.2%) for ADHD (Table 2).

Six Stages of Engagement

Parents described 6 stages in the process of seeking care for their child's ADHD (Fig 1). Parents often described stages in a predictable order as they journeyed through diagnosis and treatment but also described some overlap among stages, deviations from the usual order, and variation in the time spent in each stage. Parents described the navigation of stages as an interplay between themselves, their families, communities, and the systems serving their child (health care, education). Barriers often occurred at points of stage mismatch between parents and providers and/or systems (ie, with parents having progressed to a later stage ahead of providers or vice versa). Successful transition through each stage facilitated progression through subsequent stages (eg, accepting), but unresolved conflicts in earlier stages interfered with subsequent stages (eg, reluctant). In Tables 3 through 8, we categorize participant quotes by stage, with subthemes representing the processes involved within each stage.

Stage 1: Normalization and Hesitation (“He’s Gonna Grow Out of It”)—In

the first stage, parents realized their child's symptoms were not normative. Parents often described a process of acceptance over years from symptom onset to when they (and others) accepted these symptoms were indicative of a problem.

Parents described hesitation to pursue evaluation too early and a preference for assuming the behavior was a developmental phase.

I just kept telling myself he’s gonna grow out of it. ... Once he gets, you know, older and he starts school and he’s in kindergarten, he has more structure, like, he’ll grow out of it, and he just didn’t.

31-year-old mother of a 7-year-old boy

Parents described worsening impairment that ultimately led to acceptance of the problem and the decision to pursue evaluation and/or treatment.

She was hyperactive but it wasn’t anything to the extent of where it’s gotten now. ... And, it just got in a snowball from there, so that’s when I took her...to a pediatrician and said...you guys should take a look at it. ... It just got to a point where she didn’t wanna go to school.

43-year-old mother of a 9-year-old girl

Learning about ADHD facilitated acceptance of the problem and engagement.

The first time around I knew nothing. There was a steep learning curve. ... Everything he did, I was reading ... “My goodness. Is that normal? ... Is that because of the ADHD or is it because of something else?” ... It was all new.

40-year-old mother of a 9-year-old girl

Stage 2: Stigmatization and Fear (“I’m Being Judged”)—Having accepted that their child’s symptoms were not normative, parents faced public and internalized stigma about ADHD, as well as other forms of discrimination, that caused reluctance to pursue treatment.

Parents perceived being blamed or judged for their child’s behavior.

Basically you are not doing a good job as a parent because you’re not putting your foot down.

36-year-old mother of an 8-year-old boy

Parents also reported feeling guilty or resenting their child.

You think, as a mom, that you did something wrong. What are people going to say?... You just can’t handle how they are at their age like normal kids. ... You don’t really want to be told that they have ADHD.

29-year-old mother of a 8-year-old boy

Parents faced negative community attitudes about ADHD treatments.

It has always scared me to put him on medication, because...if you give them that, they will stay addicted, or people will call them crazy.

34-year-old mother of a 10-year-old boy

Parents feared telling others or asking for help because of concern about how they would be perceived and whether they would be taken seriously.

When it comes to the African American community...a lot of times you’re told to pray, or...you have to be the strong Black woman or...this masculine man...so a lot of times we don’t seek help...and when we do, we’re not taken seriously. They’re dismissive, as if you’re just here because you want the meds.

43-year-old mother of a 9-year-old girl

Stage 3: Action and Advocacy (“Like the Lone Wolf”)—Parents reported they were the best advocate for their child’s treatment, alone, often facing conflicting opinions about treatment and unfriendly systems.

I’m in the middle of doing what’s best for my sons and in the middle of what people says and what my family says, even what their dad believes or not. ... Whether I make the right or wrong choice, it’s always going to follow me.

29-year-old mother of an 8-year-old boy

Parents faced providers who were not ready to acknowledge the problem or take action on behalf of their child.

I have my concern. I expressed it to the doctors, but they were never concerned, they never looked at it in depth. They never listen to me.

42-year-old mother of a 10-year-old boy

Gaining knowledge and receiving support from professionals and peers empowered parents.

At the end of the day, I'm really going to be the only one that makes sure they get the best care. So, I just make sure I go above and beyond to take in everything that I learn, take in everything that's said to me, all the advice that's given to me. And like I said, research helps me a lot.

38-year-old mother of a 16-year-old girl

Stage 4: Communication and Navigation (“Four More Villages”)—Parents reported that ADHD care involved navigating systems to connect with a team of service providers in multiple realms. Navigating the system and coordinating providers could be overwhelming but improved with good care coordination and communication.

Parents emphasized the difficulty managing a child with ADHD alone and the need for more help than with neurotypical children.

It's not easy to deal with it. It takes a village to raise a child. But a child with ADHD needs three or four more villages, and ...it's life consuming.

42-year-old mother of a 10-year-old boy

Parents described feeling frustrated and overwhelmed by difficulty accessing and coordinating care, including related to logistics, cost, and transportation.

It was kind of hectic because she had so many services in place and I was overwhelmed ... I felt like giving up. It was just too much on me.

43-year-old mother of an 8-year-old girl

Parents valued good communication with and between treating providers.

Myself and his behavioral health in school and [therapist]. All of them. His primary care. Everybody that he's been involved with, we had a meeting...before he got his IEP [individual education plan], and then we all made an agreement.

44-year-old mother of a 10-year-old boy

Stage 5: Care and Validation (“He Said I Was Right”)—Parents valued long-term, trusting relationships with service providers who provided support, validation, and reassurance throughout treatment.

Parents disliked providers who performed the minimum and agencies with high staff turnover.

The negative piece of all of the services that we have...had is, unfortunately, the job is a very, very high burnout job...when you get comfortable with somebody and the kids form a relationship with that person, they leave. ...

40-year-old mother of a 9-year-old girl

Ongoing fear of stigmatization or discrimination created skepticism.

I take the doctor's advice and everything and I do my own research when I leave ... I make my own decisions for my own kids.

38-year-old mother of a 16-year-old girl

On the other hand, caring and dependable providers built trusting relationships and engaged families in treatment.

They're very concerned. They listen to me. They make me feel comfortable that they're there for my kids and me at the same time.

62-year-old mother of a 10-year-old girl

Parents sought validation of their struggles, reassurance about treatment, and their own supports.

Seeing a therapist myself. It helps a lot, so I'll be able to get off my back what I have held inside instead of yelling at her...because it's really hard dealing with a kid that has ADHD.

43-year-old mother of an 8-year-old girl

Stage 6: Preparation and Transition (“Life Is Not Easy”)—Parents described the process of preparing their child for the future and worried about ADHD interfering with future academic and occupational success.

I feel like if his lack of attention and the concentration gets in the way of his schooling, then it's like, what kind of job will he have? Even in the trades you have to pay attention.

42-year-old mother of a 10-year-old boy

Preparation for independence was a strong treatment motivator.

They're always going to be choosing bad choices. I can see it. It's going to be a huge problem in their life when they get older. I'm trying to prevent it now by getting all this help.

62-year-old mother of a 10-year-old girl

Some parents described discussing the diagnosis of ADHD with their child to encourage self-management skills and to preempt misinformation.

I told him, “Everybody's different. Some people need extra help with certain things. Some people don't.” I try to express to him as much as possible that no matter what he's still going to be loved. But I told him it's always good to be different.

29-year-old mother of an 8-year-old boy

Parents' or providers' reluctance to accept the diagnosis, stigma and fear, or skepticism about treatment caused hesitation to discuss ADHD directly with the child and prepare them for a future with ADHD.

It's like a labeling thing.... You don't want your kid to feel uncomfortable. And the next thing you know, “I don't want to go to school anymore.”

33-year-old mother of a 9-year-old girl

DISCUSSION

Thematic analysis of in-depth interviews with parents of children with ADHD uncovered 6 stages of engagement in ADHD care, starting with acceptance that symptoms were not normative and advancing through preparation for the child's independent future. Parents described each stage as a milestone preparing them for the next and had success when support from providers matched their own stage of engagement. Authors of previous studies have reported some similar themes, but none have provided a comprehensive framework with a developmental trajectory navigated by parents and providers together, which could serve as a model for developing and tailoring engagement interventions.

Other qualitative studies have described specific stages of our model. For example, in a qualitative study on treatment-seeking with diverse parents of children with ADHD, Leslie et al³³ reported 4 patterns reflecting different progressions through stage 1. They reported that low-income Spanish-speaking families were more often reluctant to accept an ADHD diagnosis or treatment, suggesting cultural influences also described by parents in our study. In another qualitative study with parents of mostly African American children with a new diagnosis of ADHD, DosReis et al⁴¹ reported that most families perceived ADHD stigma, with many similarities to stigma described by our parents in stage 2, including self-blame and dismissiveness by medical providers. Brinkman et al³⁴ conducted a qualitative study with 75% non-Hispanic white and 25% non-Hispanic Black parents to understand their decision-making about ADHD treatment. Parents described the importance and process of accepting an ADHD diagnosis (as in stage 1), sometimes facing stigma as a barrier to treatment (as in stage 2), and need for ongoing validation of treatment decisions, including contrasting time on and off medications (as in stage 5).

Our findings suggest that typical measures of treatment engagement do not capture the full extent or spectrum of family engagement in care. The most commonly used measures of treatment engagement (eg, appointments attended or prescriptions filled¹⁹) are systems oriented and provider centered and do not inform strategies to improve or measure engagement tailored for individual families. On the other hand, 2 existing measurement tools capture important elements of the engagement process we describe that could be used proactively in the treatment process. The ADHD Preference and Goal Instrument⁴² helps assess a family's preferences for and hesitations about behavioral therapy and medication management as well as overall treatment goals. The instrument includes questions about stigma, hesitation about treatment, willingness to engage, and feasibility of different treatments. Another tool, the ADHD Stigma Questionnaire,⁴³ was adapted from the HIV Stigma Questionnaire and assesses perception of stigma encountered by people with ADHD, although it has not been tested for use with parents or in a clinical setting. The 6 stages framework could be used as a guide to develop more tools to measure a family's engagement stage and thus help systems and providers better respond to individual families' needs, tailor treatment recommendations, and individualize outcomes assessments.

Staging models are not new to behavioral health. The most well-known stage model in behavioral health care, the transtheoretical model (ie, stages of change model),^{44,45} was originally developed in the 1970s from studies of smoking cessation. For decades, the

transtheoretical model has provided a successful blueprint for expanding and personalizing behavioral and substance abuse intervention strategies through a process of stage matching.⁴⁶ Similarly, using the 6 stages framework could allow the health system to better match the needs of children with ADHD whose families are at different stages of their engagement process. For example, in stage 2 (stigmatization and fear), parents explained how discrimination based on race or ethnicity intersected with ADHD stigma in their community to delay care. Interventions that target discrimination and stigma could include antiracism training for treaters and a family-oriented component addressing misconceptions about ADHD, bridging explanatory models, and brainstorming responses to stigmatizing statements. In stage 6, even parents with young children grappled with how to prepare their child for the future and communicate with them about ADHD. Most research on transitioning to independence with ADHD targets adolescents,^{47,48} but our findings suggest that interventions facilitating parent-child discussion about ADHD should begin earlier.

Our study has multiple strengths. Our sample included primarily parents of low-income and racial and ethnic minority youth, who are most likely to experience difficulty engaging with care. We conducted interviews in 3 languages, increasing the diversity of important perspectives on ADHD care engagement. We used rigorous qualitative methods, including double-coding with reliability tracking and an intensive group axial coding process. Finally, our study design, which was intended to inform intervention development, yielded clinically relevant findings with immediate clinical application.

Limitations of our study include that we recruited from 1 safety net hospital system, and so our findings may not apply to other settings. We recruited a clinical sample and thus do not have perspectives from families with children not diagnosed with or treated for ADHD, who should be included in future studies on engagement in care. We did not have quantitative information on years of treatment or age at diagnosis, which would have added a useful dimension to triangulate findings. We included diverse families but did not identify how families of specific racial or ethnic groups might progress differently through the stages, which could further inform use of the 6 stages model.

CONCLUSIONS

Our qualitative study revealed 6 stages of engagement in ADHD treatment described by parents of predominantly racial and ethnic minority children with ADHD. Parents described each stage as both a barrier to overcome and a milestone to navigate. Stage mismatch between parents and providers caused difficulty and conflict and interfered with engagement. Our findings have important implications for the measurement of engagement and the development of family-centered interventions to improve engagement in ADHD treatment.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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ABBREVIATIONS

ADHD	attention-deficit/hyperactivity disorder
BMC	Boston Medical Center

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WHAT'S KNOWN ON THIS SUBJECT:

Attention-deficit/hyperactivity disorder (ADHD) is a common, treatable pediatric condition, but racial and/or ethnic minority families experience disproportionate barriers to treatment engagement. Beyond identifying discrete barriers to care, the field lacks a family-centered framework to guide development of ADHD engagement interventions.

WHAT THIS STUDY ADDS:

Using qualitative methods, we discovered 6 stages of engagement in ADHD treatment described by diverse parents. The stages unfolded like a developmental process, hampered by stage mismatch between parents and providers. Difficulty resolving earlier stages interfered with navigating later stages.

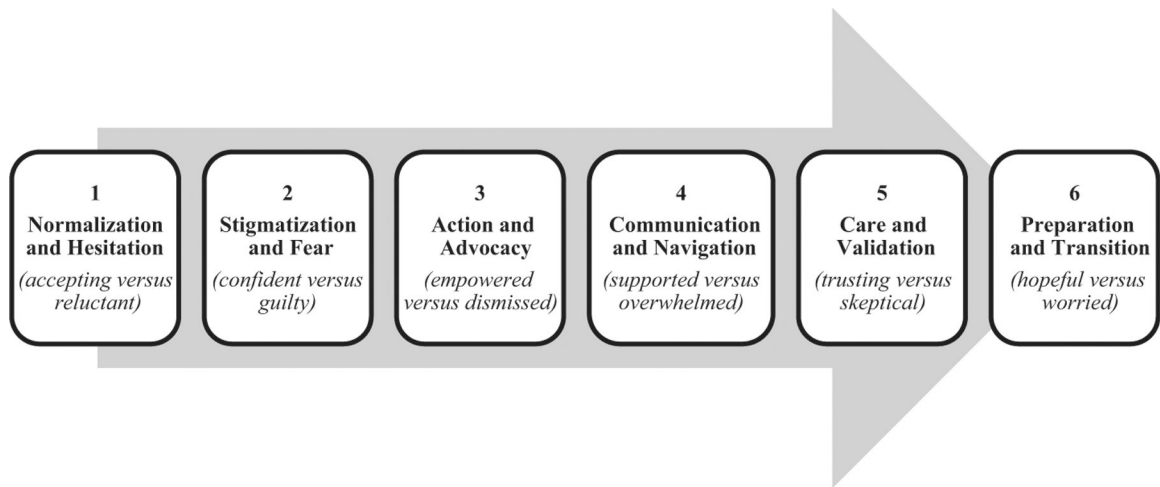


FIGURE 1.

Six stages of engagement in ADHD care, as described by parents. Parents described 6 stages of engagement in care for ADHD, depicted along with their successful versus unsuccessful resolution. Unresolved difficulties with any 1 stage remained a barrier to navigating subsequent stages.

TABLE 1

Characteristics of Parent Participants

	N = 41
Age, mean \pm SD, y	40.8 \pm 7.6
Sex, n (%)	
Female	38 (92.7)
Male	3 (7.3)
Marital status, n (%)	
Married or living with a partner	20 (48.8)
Divorced or separated	6 (14.6)
Never married	15 (36.6)
Study visit language, n (%)	
English	31 (75.6)
Spanish	9 (21.9)
Haitian Creole	1 (2.4)
Primary language spoken at home, n (%)	
English	29 (70.7)
Spanish	10 (24.4)
Haitian Creole	2 (4.9)
Birthplace, n (%)	
In the United States	24 (58.5)
Outside the United States	17 (41.5)
Puerto Rico	4 (23.5)
Mexico	3 (17.7)
Guatemala	2 (11.8)
Haiti	2 (11.8)
Jamaica	2 (11.8)
Bulgaria	1 (5.9)
El Salvador	1 (5.9)
Dominican Republic	1 (5.9)
Ghana	1 (5.9)

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N = 41	
Education level, <i>n</i> (%)	
Less than high school degree	10 (24.4)
High school degree or GED	10 (24.4)
Postsecondary education	14 (34.1)
College degree or higher	7 (17.1)
Employed at least 50 of 52 wk, <i>n</i> (%)	25 (60.9)
Household income, median (range), \$	20 000 (0–200 000)

GED, general educational development.

TABLE 2

Demographic and Clinical Characteristics of Children With ADHD

Sex, <i>n</i> (%)	<i>N</i> = 41
Male	27 (65.9)
Female	14 (34.1)
Age, mean \pm SD, y	11 \pm 3.3
Age group, <i>n</i> (%)	
3–5 y old	1 (2.4)
6–11 y old	24 (58.5)
12–17 y old	16 (39)
Ethnicity, <i>n</i> (%)	
Hispanic, Latino, or Spanish origin	15 (36.6)
Not of Hispanic, Latino, or Spanish origin	26 (63.4)
Race, <i>n</i> (%)	
Black or African American	23 (56.1)
White	8 (36.6)
American Indian or Alaskan native	2 (4.9)
Asian American, native Hawaiian, or other Pacific Islander	0 (0)
Other race	6 (14.6)
> 1 race	5 (12.2)
Health insurance, <i>n</i> (%)	
Public	25 (62.5)
Commercial or private	15 (37.5)
Other psychiatric conditions, <i>n</i> (%)	
Behavioral or conduct problem	25 (61)
Depression or anxiety	16 (39)
Any other mental health condition	2 (4.9)
Other developmental conditions, <i>n</i> (%)	
Speech or other language	12 (29.3)
Learning disabilities	12 (29.3)

	N = 41
Developmental delay	10 (24.4)
Medical conditions, <i>n</i> (%)	
Asthma	18 (43.9)
Allergies	17 (41.5)
Epilepsy or seizures	2 (4.9)
Frequent headaches, including migraine	2 (4.9)
Arthritis	1 (2.4)
Treatment history, <i>n</i> (%)	
Ever taken medication for ADHD	40 (97.6)
Currently taking medication for ADHD	38 (97.4)
Ever received therapy	36 (87.8)
Currently has special school services	37 (90.2)
Repeated a grade, <i>n</i> (%)	5 (12.2)
CBCL syndrome scales, mean (SD)	
Anxious or depressed	58.6 (9.4)
Withdrawn or depressed	59.7 (7.7)
Somatic complaints	60.1 (9.9)
Social problems	60.6 (8.3)
Thought problems	61.4 (8.5)
Attention problems	65.7 (7.0)
Rule-breaking behavior	60.9 (7.4)
Aggressive behavior	64.5 (9.8)
Borderline and clinically elevated CBCL scales, <i>n</i> (%)	
Anxious or depressed	10 (27)
Withdrawn or depressed	10 (27)
Somatic complaints	10 (27)
Social problems	9 (24.3)
Thought problems	13 (35.1)
Attention problems	23 (63.9)
Rule-breaking behavior	10 (27)
Aggressive behavior	15 (42.9)

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TABLE 3
Selection of Representative Parent Quotes on Engaging in ADHD Treatment Stage 1: Normalization and Hesitation (“He’s Gonna Grow Out of It”)

Subcategory	Normalization and Hesitation Quotes (Representative Selection)	Parent and Child Information
Hesitation	<p>“I just kept telling myself he’s gonna grow out of it... Once he gets, you know, older and he starts school and he’s in kindergarten, he has more structure, like, he’ll grow out of it, and he just didn’t.”</p> <p>“Well imagine that when they told me I had doubted it, that’s why I didn’t want to give him pills, I did that later. I thought, ‘It cannot be happening, no. My child does not have that....’ But like I told you...but seeing that he was dropping grades, I previously said no, but then I said yes to the pill. That’s when I was convinced that he had that.”</p> <p>“When they diagnosed them of ADHD and the behaviors that they was doing, I said to them, ‘I just don’t understand because they’re up to age and they should know better. And I see that in different situations, how it can be controlled. Yet, you all diagnosed them as ADHD. I still don’t really understand it too much.’ But they diagnosed them with that.”</p> <p>“And, I find that a lot of even her own dad, he doesn’t think she has ADHD. He keeps telling me, ‘Oh, it’s just growing pains. She’s just a child growing up. This is what they do.’”</p> <p>“Because I was tired, you know. After I came out of that denial state, I started to accept it. And so, I think that’s what a lot of parents... sometimes could be in denial because you don’t want a kid that has, you know, any issues.”</p> <p>“And, it just got in a snowball from there, so that’s when I took her...to a pediatrician and said...you guys should take a look at it.”</p> <p>“Well, the old school that she was in at first, the one that she got kicked out of, was the one that picked up and felt like something was going on with her because she couldn’t stay focused.... Then the hospital picked up on it, so then we wound up sending her to a specialist, which the specialist, they ran tests and all different types of things and they found out that she did have it.”</p> <p>“When we first met her she was pretty much sure this is what was happening with him, because he would just be all over the place unable to focus on anything, touching everything. To me, it was him being a child. I don’t know. So things started getting a little bit out of hand at home with him.”</p> <p>“Actually, it was pretty good when they were working with me. I just didn’t want to accept that he was diagnosed with ADHD because I really didn’t understand like the ADHD. I didn’t know what it was until we started working with these, there was like agencies that were coming in the home working with him too.”</p> <p>“The first time around I knew nothing. There was a steep learning curve...it was like a new world with my first child with ADHD and that was tough because I didn’t know what to expect. Everything he did, I was reading... ‘My goodness. Is that normal?... Is that because of the ADHD or is it because of something else?’... It was more of a nerve-wracking experience because it was all new.”</p> <p>“Just give them more information. It’s a real thing. It has real treatment. And, it can affect your kids’ success long-term. I really do think that the most important piece is that it affects how they feel about themselves.”</p> <p>“I’ve already been through it with my daughter. My daughter is 26 years old. She was diagnosed with ADHD when she was six.... Everything I’m going through with him, I already been through with my daughter. So I learned over the years to have more patience and understanding....”</p>	<p>31 y-old mother of a 7 y-old boy</p> <p>49 y-old mother of a 11 y-old boy</p> <p>62 y-old mother of a 10 y-old girl</p> <p>43 y-old mother of a 9 y-old girl</p> <p>50 y-old mother of a 10 y-old boy</p> <p>43 y-old mother of a 9 y-old girl</p> <p>43 y-old mother of an 8 y-old girl</p> <p>36 y-old mother of an 8 y-old boy</p> <p>51 y-old mother of a 17 y-old boy</p> <p>40 y-old mother of a 9 y-old girl</p> <p>49 y-old mother of a 14 y-old boy</p> <p>42 y-old mother of a 13 y-old boy</p>
Worsening impairment leading to acceptance		
Learning about ADHD facilitating acceptance		

Selection of Representative Parent Quotes on Engaging in ADHD Treatment Stage 2: Stigmatization and Fear (“I’m Being Judged”)

TABLE 4

Subcategory	Stigmatization and Fear Quotes (Representative Selection)	Parent and Child Information
Others blaming or judging parent and/or child	<p>“When I’m talking to other people, I feel like I’m being judged... even if they’re not saying it... cause they’ll say something stupid like, ‘Why don’t you do this? Why don’t you...?’ You don’t understand what I’m going through right now, so don’t tell me what I should and should not do.”</p> <p>“Sometimes I feel like I am being blamed, or I’m not...according to other people...I’m not parenting correctly, because she can’t control herself.”</p> <p>“A lot of people it’s like, ‘Oh, you spoil her. You let her do this, you let her do that.’ That’s the only thing I got judged about. It’s letting her get away with things — ‘There were no boundaries in the home.’”</p> <p>“I feel bad because, even though no one has ever told me this, I know that people tend to reject people who suffer from it.”</p> <p>“They started blaming him for everything.... My son is like this because now he’s used to being blamed for anything and everything, and it does not matter what he says. He always gets shut down.”</p>	<p>42-y-old mother of a 13-y-old boy</p> <p>40-y-old mother of a 3-y-old girl</p> <p>28-y-old mother of an 6-y-old girl</p> <p>34-y-old mother of a 10-y-old boy</p> <p>36-y-old mother of an 8-y-old boy</p>
Parent blaming themselves or child	<p>“It was difficult and scary, because I don’t know. You think, as a mom, that you did something wrong. What are people going to say? Are you sure? You just can’t handle how they are at their age like normal kids. What’s really wrong? You don’t really want to be told that they have ADHD or anything like that.”</p> <p>“For the longest time, because we didn’t know what was going on, we kind of blamed her...I thought she was just being a stubborn kid, and I’m like, ‘Why are you being so...why can’t you just listen?’ ... you know.”</p> <p>“Sometimes I used to blame myself. Well, maybe it’s because of me because he got ADHD. So, that really just sat on my brain. I really went through some problems with that. He has ADHD because of me.”</p>	<p>29-y-old mother of an 8-y-old boy</p> <p>43-y-old mother of a 9-y-old girl</p> <p>51-y-old mother of a 17-y-old boy</p>
Facing negative attitudes about ADHD treatment	<p>“Well they were saying ADHD basically, is a fake diagnosis. That’s sort of like some things they were saying...that was sort of the negative things they were saying.”</p> <p>“The biggest thing was the medications because you start hearing things. They will outgrow it, they don’t want to listen. I’ve heard it all.”</p> <p>“It was what everyone told me. Do not give him medication that is used here so that the teachers do not have too much work from all the children so they want to give him medicine.”</p> <p>“That’s the main fear. Even in the beginning I was on edge with my son being on the medication. There have been studies that show doctors are quick to give African American children medication for this and that.”</p>	<p>28-y-old mother of a 6-y-old girl</p> <p>36-y-old mother of an 8-y-old boy</p> <p>40-y-old mother of an 8-y-old boy</p> <p>30-y-old mother of a 12-y-old boy</p>
Fear of asking for help or disclosing diagnosis	<p>“I feel like a lot of people don’t like to do the therapist thing because they think it’s weird, I guess. [But], I feel like, if your kid needs it...it will make them better. So...don’t stop yourself from doing it.... A lot of people think that therapy is for crazy people or something like that...it’s not like that at all.”</p> <p>“I feel like sometimes doctors do think parents exaggerate, and I know parents sometimes do, but they shouldn’t just put everybody in the same category...I know a lot of parents are not able or willing to speak to the doctors because of that, because they know that they’re not going to be listened to anyways or heard. They’re just going to be dismissed, so what’s the point sometimes?”</p> <p>“When it comes to the African American community...culturally...a lot of times you’re told to pray, or...you have to be the strong Black woman or...this masculine man...so a lot of times we don’t seek help...and when we do, we’re not taken seriously. They’re dismissive, as if you’re just here because you want the meds.”</p> <p>“Yeah, they say ‘If you have anxiety, depression, or attention-deficit disorder, you’re crazy.’ It doesn’t matter how much you explain to them what it is, it’s honestly better not to say anything at all.”</p>	<p>29-y-old mother of an 8-y-old boy</p> <p>43-y-old mother of a 9-y-old girl</p> <p>34-y-old mother of a 10-y-old boy</p>

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Subcategory	Stigmatization and Fear Quotes (Representative Selection)	Parent and Child Information
	“When I’m talking to somebody else that don’t have any kids, I get negative feedback. So, I just don’t talk about it too much until I get with their therapist.”	62-y-old mother of a 10-y-old girl

Selection of Representative Parent Quotes on Engaging in ADHD Treatment Stage 3: Action and Advocacy (“Like the Lone Wolf”)

TABLE 5

Subcategory	Action and Advocacy Quotes (Representative Selection)	Parent and Child Information
Parents advocating alone	<p>“I’m in the middle of doing what’s best for my sons, and in the middle of what people says and what my family says, even what their dad believes or not...I don’t know all the answers sometimes. Whether I make the right or wrong choice, it’s always going to follow me.”</p> <p>“It was just in the beginning just getting everything together, because it’s just me, single mom. I don’t have nobody. So, that’s the hard part, but I always get it done.... And if I can’t, I’ll...reschedule it, but sometimes it is hard, just being strap for cash and time and dedication....”</p> <p>“Well, I always ask who’s willing to help but, the decisions are finally made by me because everyone has a very different opinion. If I can ask my close friends who do not have a child with the problem, they will tell me, ‘Do not give him medication.’ It was what everyone told me.”</p> <p>“I’m like, ‘You’re entitled to your opinion. I’m entitled to mine. And she’s my daughter. So, I will do whatever I feel is fit to keep her nice and healthy, and safe. So until you start raising her, or paying her bills, you have nothing to say to me. And if you do, I have the right to choose whether I agree with you, or whether I don’t.’”</p> <p>“I have my concern. I expressed it to the doctors, but they were never concerned, they never looked at it in depth. They never listen to me.... They let it pass.”</p> <p>“So, when I discovered the problem he had, I began to cry because I thought about the 5+ years of the same complaints the school gave me and without knowing what could really....”</p> <p>“I had already noticed but they did not want to hear me...I talked to his pediatrician and I told him what I was seeing about my son, because it was not normal.... Well no, the pediatrician told me that it was normal. Then...when he came to school...there were many [teachers] that called me that I had to talk to the doctor...and that was when they gave him...medicine.”</p> <p>“A lot of times kids, especially Black kids, they’re stereotyped in a way, you know, thinking that ADHD not really...they don’t really have it. It’s just a behavioral issue, and maybe the parents are not being stern enough or something like that. I feel that that happens quite often...being a Black or an African American, it’s truly a challenge. You’re not taken as seriously as say someone of a different race if you go in....”</p> <p>“Telling a doctor ‘Hey, my son has been going through this and I don’t think it’s normal’ and getting a response like ‘Oh, that’s just’ or ‘There’s nothing wrong with him.’”</p> <p>“I think right now I think I feel very engaged because at the end of the day, I’m coming to them and I’m explaining to them my concerns and what I feel I need help with and they’ll help me.”</p> <p>“So...what could I do?...I did the best I could to learn a little bit about the 504 Plan...I got the school to give him a 504 Plan until I collected enough information about the IEP which was a puzzle. It took me a whole year to understand...I said, ‘Why don’t they give services to my son without an IEP?’ Then, I understood that, you know, it had to do with the state and the funds, and the school not wanting to pay extra services.”</p> <p>“I’ve just read about it a lot. I really like reading, in fact, I’ve always said that people must read in order to know what to answer, otherwise just keep quiet. It’s a decision that I made on my own, because in Puerto Rican’s culture, taking pills means you are crazy.”</p> <p>“At the end of the day, I’m really going to be the only one that makes sure they get the best care. So, I just make sure I go above and beyond to take in everything that I learn, take in everything that’s said to me, all the advice that’s given to me. And like I said, research helps me a lot.”</p> <p>“It is overwhelming but it’s part of being a parent. Children are a blessing and I would say keep pushing forward. Communicate with the doctors, speak to the teachers. If the teachers are not telling you what you want to hear don’t be afraid to...ask to speak to a supervisor. If you don’t advocate for your child nobody else will.... As a parent you have to do your research. These people are here to provide us with support and the information.”</p>	<p>29-y-old mother of an 8-y-old boy</p> <p>36-y-old mother of a 13-y-old girl</p> <p>40-y-old mother of an 8-y-old boy</p> <p>40-y-old mother of a 3-y-old girl</p> <p>42-y-old mother of a 10-y-old boy</p> <p>41-y-old mother of a 15-y-old boy</p> <p>48-y-old mother of a 14-y-old boy</p> <p>43-y-old mother of a 9-y-old girl</p> <p>34-y-old mother of a 10-y-old boy</p> <p>28-y-old mother of a 6-y-old girl</p> <p>42-y-old mother of a 10-y-old boy</p> <p>34-y-old mother of a 10-y-old boy</p> <p>38-y-old mother of a 16-y-old girl</p> <p>30-y-old mother of a 12-y-old boy</p>

IEP, individual education plan.

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Selection of Representative Parent Quotes on Engaging in ADHD Treatment Stage 4: Communication and Navigation (“Four More Villages”)

TABLE 6

Subcategory	Communication and Navigation Quotes (Representative Selection)	Parent and Child Information
Need for help	<p>“It’s not easy to deal with it. It takes a village to raise a child. But a child with ADHD needs three or four more villages, and...it’s life consuming.”</p> <p>“Myself and his behavioral health in school and Home For Little Wanderers. All of them. His primary care. Everybody that he’s been involved with, we had a meeting for it and made a decision. Like, speech therapy, everybody.”</p> <p>“Nothing has been negative at all because I see they’re really working hard. They’re very concerned. They listen to me. They make me feel comfortable that they’re there for them and me at the same time, but it’s up to the child.”</p> <p>“The main barrier is that a lot of time you feel like your hands are tied because you don’t know what else to do - where else to look, where to find more help, what help I should be looking for.”</p> <p>“It took me 3 or 4 months to finally get an appointment. The pediatrician doesn’t prescribe medicine, though; the psychiatrist does, so you have to wait for them to give it to you.”</p> <p>“In the research I did on the Internet, there are tutoring that you have to pay for and they are quite expensive and I can’t afford them. That’s the reason why...he’s not receiving everything, because I haven’t yet found a place that offers them at an affordable price or for free.”</p> <p>“Sometimes I don’t have the funds to take her to her appointment or to go get the medication for her.”</p>	<p>42-y-old mother of a 10-y-old boy</p> <p>44-y-old mother of a 10-y-old boy</p> <p>62-y-old mother of a 10-y-old girl</p> <p>32-y-old mother of an 8-y-old boy</p> <p>34-y-old mother of a 10-y-old boy</p> <p>32-y-old mother of an 8-y-old boy</p> <p>43-y-old mother of an 8-y-old girl</p> <p>39-y-old mother of an 8-y-old girl</p> <p>43-y-old mother of an 8-y-old girl</p> <p>40-y-old mother of a 3-y-old girl</p> <p>34-y-old mother of a 14-y-old boy</p>
Difficulty coordinating care	<p>“If you don’t have money to pay for special programs, then you can’t do anything. And if you don’t have money to have a car to transport your kid to those programs that you can find for free, then you are lost.”</p> <p>“I’m just maxed out sometimes. You know, but the pharmacy, they would tell me, ‘Oh, it’s not gone through, they’re not going to pay for it.’ Stuff like that. And I had to wait in the car, call them and ask what’s going on, and go back and forth with the insurance.”</p> <p>“For example, when they receive psychological and psychiatric therapy, the fact that both parties are not communicating is a very big conflict. I had a very bad experience where I had two different diagnoses and, instead of communicating with each other, they would try and make their reasoning sound better than the other one.... It was frustrating.”</p> <p>“All the questions that I have asked, the psychiatrist...helped me well with understanding a lot about her diagnosis and how the medicine benefits are, and what the medicine does for her.”</p> <p>“Also, his primary care doctor, she is great. I can shoot her a message.... and she calls me. If I have any issues they are great with communicating.”</p> <p>“Myself and his behavioral health in school and [therapist]. All of them. His primary care. Everybody that he’s been involved with, we had a meeting for it and made a decision. Like, speech therapy, everybody. Like, before he got his IEP, and then we all made an agreement.”</p>	<p>42-y-old mother of a 10-y-old boy</p> <p>40-y-old mother of an 8-y-old boy</p> <p>40-y-old mother of a 17-y-old boy</p> <p>28-y-old mother of a 6-y-old girl</p> <p>30-y-old mother of a 12-y-old boy</p> <p>44-y-old mother of a 10-y-old boy</p>
Importance of communication with and between providers		

Subcategory	Communication and Navigation Quotes (Representative Selection)	Parent and Child Information
	<p>“They helped me with the IEP and getting all his papers together. His doctors help with helping him with the psychiatrist and making all appointments and the medication and all that stuff. So, we were all trying to be a team player in this thing. I guess everything worked out.”</p>	<p>51-y-old mother of a 17-y-old boy</p>

IEP, individual education plan.

Selection of Representative Parent Quotes on Engaging in ADHD Treatment Stage 5: Care and Validation (“He Said I Was Right”)

TABLE 7

Subcategory	Care and Validation Quotes (Representative Selection)	Parent and Child Information
Problem with providers doing the minimum	<p>“It’s a lot of ‘It’s my job.’ No. If that’s the case, then you’re doing your job incorrectly because you’re not helping families. Your job is to help families.”</p> <p>“The negative piece of all of the services that we have... had is, unfortunately, the job is a very, very high burnout job... when you get comfortable with somebody and the kids form a relationship with that person, they leave.... My biggest negative complaint is the turnover.”</p> <p>“And then after the interview was over, she told me, ‘Oh, um, we don’t, we can’t provide any services for him because he’s ADHD.’ I said, ‘I mean, but what are you guys there for?’ you know. But... I told... the people that brought them, you know, referred them to me. I told them and they said that they wasn’t supposed to do that. They supposed to give him treatment.... The minute they met my son and they interviewed him... they didn’t want to deal with him.”</p>	<p>34-y-old mother of a 14-y-old boy</p> <p>40-y-old mother of a 9-y-old girl</p> <p>42-y-old father of a 14-y-old boy</p>
Skepticism	<p>“I take the doctor’s advice and everything and I do my own research when I leave. And I take everybody’s advice into consideration, base it off my research and I make my own decisions for my own kids. That’s just something that I learned a long time ago. They’re my kids.”</p> <p>“You’re basically taking what the doctors or whoever is telling you and they could be telling you anything. Because I noticed how a lot of doctors... they’re just pushing these meds on you because they have to for these pharmaceutical people and things like that. So it’s like, how would you really know? Do your own research.”</p> <p>“Work with people that’s interested in helping you.”</p>	<p>38-y-old mother of a 16-y-old girl</p> <p>38-y-old mother of a 16-y-old girl</p> <p>47-y-old mother of a 9-y-old boy</p> <p>42-y-old father of a 14-y-old boy</p>
Caring and dependable providers	<p>“For me, a doctor is everything because she’s the one that takes care of all of us... prevent bad things from happening to us, make sure that we are all healthy.”</p> <p>“They’re very concerned. They listen to me. They make me feel comfortable that they’re there for my kids and me at the same time.”</p> <p>“We had a behavioral analyst specialist as well. He was the absolute savior for what was happening at home, and to teach me how to deal with my son.”</p>	<p>62-y-old mother of a 10-y-old girl</p> <p>36-y-old mother of an 8-y-old boy</p>
Seeking validation	<p>“Support from my mom, and reassurance from the doctors and stuff, really helped.”</p> <p>“I mentioned to her doctor about it a while back actually, her PCP, and she was really active unable to stay on one task even at home. So, the doctor was seeing some the behaviors in the doctor’s office and I brought it to her attention.”</p> <p>“One day I took my son to a consultation unmedicated and he was able to see the difference, I was like ‘You see? There’s a big difference’ and he said I was right.”</p>	<p>26-y-old mother of a 10-y-old boy</p> <p>28-y-old mother of a 6-y-old girl</p> <p>34-y-old mother of a 10-y-old boy</p>
Parent support	<p>“Seeing a therapist myself. It helps a lot, so I’ll be able to get off my back what I have held inside instead of yelling at her... because it’s really hard dealing with a kid that has ADHD.”</p> <p>“Self-care is extremely important... I do have my allotted time during the week, you know, to meet with my own therapist and try to do self-care for myself.”</p>	<p>43-y-old mother of an 8-y-old girl</p> <p>40-y-old mother of a 9-y-old girl</p>

PCP, primary care provider.

Selection of Representative Parent Quotes on Engaging in ADHD Treatment Stage 6: Preparation and Transition (“Life Is Not Easy”)

TABLE 8

Subcategory	Preparation and Transition Quotes (Representative Selection)	Parent and Child Information
Concern about child's future	“I hope that she's able to overcome these things and be able to get a good job...and a good education.”	40-y-old mother of a 3-y-old girl
	“I feel like if his lack of attention and the concentration gets in the way of his schooling, then it's like, what kind of job will he have? Even in the trades you have to pay attention, you need to learn what to do.”	42-y-old mother of a 10-y-old boy
Preparation for independence	“I don't know what's going to happen to him when he grows up because I have [another] son who has the same type of problems and it's been a struggle with my son.”	50-y-old mother of a 13-y-old boy
	“But...I've got to let go a little bit, because if I keep doing this, then he's not going to learn to cope at all. And then, God forbid, I'll probably make him even more worse than he already is...I've got to sit back and let him try to figure this out because I'm not going to be around here forever.”	34-y-old mother of a 14-y-old boy
	“They're always going to be choosing bad choices. I can see it. It's going to be a huge problem in their life when they get older. I'm trying to prevent it now by getting all this help, [counseling].”	62-y-old mother of a 10-y-old girl
	“I think that's one of the positives about getting them treatment or help with the doctor, that I'm able to trust that they're going to be okay.”	29-y-old mother of an 8-y-old boy
Discussing ADHD with child	“I want her to become a productive... I say this to her every day. ‘My goal is for you to grow up to be a productive member of society. What that is is you need to be contributing, paying your own bills, making your own way in life, not depending on someone, no one. You're supposed to be independent of...you're gonna be better than I am right at this point,’ you know?”	43-y-old mother of a 9-y-old girl
	“I told him, ‘Everybody's different. Some people need extra help with certain things. Some people don't.’ I try to express to him as much as possible that no matter what he's still going to be loved...I told him it's always good to be different. He doesn't have to be like everybody else.”	29-y-old mother of an 8-y-old boy
Hesitation to discuss ADHD with child	“I tell her all the time. ‘Life is not easy. It's not. You're gonna find a lot of challenges out there but you having ADHD is gonna be a little bit more difficult for you. And so, you have to learn to navigate the best way you can, and that's what I'm here for.’”	43-y-old mother of a 9-y-old girl
	“They just have to know it's okay and what I tell my son is, ‘You are not dumb, you are not ugly. You have a mirror. When you get up in the morning you look at yourself. Do you like yourself?’ I like myself, Mommy.’ ‘That's all that matters.’”	36-y-old mother of an 8-y-old boy
	“I just got to have more patience, more understanding, more, you know. Especially more like communication with your kid...with him. When your kid has that kind of problem you need to have more communication. See, try to go into their world. See how they feel, what they think, you know what I mean? And I try to do that with my son.”	42-y-old mother of a 13-y-old boy
	“I want him to always know that, to be confident in yourself with who you are regardless of what anyone around you thinks or regardless of what statistics show about ADHD.”	30-y-old mother of a 12-y-old boy
	“It's like a labeling thing.... You don't want your kid to feel uncomfortable. And the next thing you know, ‘I don't want to go to school anymore.’”	33-y-old mother of a 9-y-old girl
	“Don't sit there and diagnose cause he's gonna feel like, ‘Wait my what? My huh? How come I'm hearing about this...from everybody, so there's something wrong with me’.... I don't want him to ever think he is different than anybody else.”	42-y-old mother of a 6-y-old boy
	“I tell him things like that so that he doesn't use these things for an excuse. Because growing up if you do something you're not supposed to do and law enforcement is involved, they don't want to hear. ‘Oh it's the ADHD.’ That doesn't matter. So I always tell him what's real.... So far by me doing that, it helps him.”	30-y-old mother of a 12-y-old boy