

THE SPECIAL NEEDS AND BEHAVIORAL SYSTEM OF CARE ASSESSMENT IN BROWARD COUNTY



ACKNOWLEDGMENTS

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Glossary of Terms

Children's Services Council of Broward County (CSC)
Special Needs Advisory Coalition (SNAC)
Special Needs System of Care Assessment (SN SOCA)
Caregiver of Youth with Special Needs Survey (CYSNS)
Broward County Public Schools (BCPS)
Autism Spectrum Disorder (ASD)
Emotional and Behavioral Disabilities (EBD)
Specific Learning Disabilities (SLD)
Attention Deficit Hyperactivity Disorder (ADHD)
Intellectual Disabilities (ID)
Traumatic Brain Injury (TBI)
Newborn Intensive Care Unit (NICU)
Florida Diagnostic and Learning Resource System (FDLRS)
South Carolina Act Early Team (SCAET)
Applied Behavior Analysis (ABA)
Physical Therapy (PT)
Occupational Therapy (OT)
Center for Hearing and Communication (CHC)
South Carolina Act Early Team (SCAET)
Early Intensive Behavioral Intervention (EIBI)
ABA (Applied Behavior Analysis)
University of Miami Center for Autism and Related Disabilities (CARD)
Autism Committee (ACE)
University of Miami Autism Spectrum Assessment Clinic (ASAC)
Parental Information Resource Center in Broward (PIRC)
American Youth Soccer Organization (AYSO)
Los Angeles Unified School District (LAUSD)
Supplemental Security Income (SSI)
Individualized Education Program (IEP)

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I EXECUTIVE SUMMARY

The report that follows describes the findings of the Special Needs System of Care Assessment in Broward County. This assessment sought to provide information that will lead to the improvement of policies related to the well-being of children and youth with special needs. Of special interest and importance was the examination of the intersection of race and ethnicity with disabilities.

The System of Care Assessment addressed three primary objectives:

- 1) Identify probable unmet service needs and gaps within the special needs system of care in Broward County with a focus on potential racial or ethnic disparities,
- 2) Identify possible community assets and resources, and
- 3) Provide findings that will allow stakeholders to develop priorities and strategies to address the identified needs and gaps as well as to utilize and mobilize existing community resources.

The System of Care Assessment employed a community based participatory approach engaging over 1,400 caregivers, and a variety of experts through surveys and focus groups. The assessment identified needs and assets that impact the lives of families of children with special needs in Broward County in the following domains:

- 1) Special need identification, screening, assessment, and referral
- 2) Access to care
- 3) Community-based services and supports
- 4) Care coordination and family-service provider partnerships
- 5) Transition support
- 6) Customer experience, and
- 7) Service disparities.

A brief summary of the findings with regard to each domain is presented below.

Special Need Identification, Screening, Assessment, and Referral

Early screening and diagnosis are essential for children with special needs to receive early intervention. In the current sample, a little more than a quarter of caregivers reported not noticing anything was wrong with their child for quite some time. Almost half of caregivers reported that extended family or elders told them that there was nothing wrong with the child, and a quarter of caregivers reported resistance from their partner in seeking help. The majority of caregivers reported being diagnosed by a specialist or primary care physician. Pediatricians may be in the best position to help with early identification and referral.

About 40% of caregivers reported not knowing where to get help at time of screening and diagnosis. Only a little more than a quarter of caregivers reported using the 2-1-1 Broward service to obtain information regarding assistance for their child with special needs. In addition, caregivers requested an improved online resource to access needed information. While www.211specialneeds.org exists, caregivers are either not aware of the resource or do not seem to find the resource adequate to meet their needs or user friendly.

The only disparity identified with respect to caregiver perceptions regarding screening and diagnosis dealt with caregivers of boys with special needs being more likely to endorse their partner resisting

getting help. Potentially, a difference in help-seeking behaviors of caregivers may exist depending upon the sex of their child. This may be related to cultural norms, and the expectations that caregivers have related to the development of boys versus girls.

Access to Care

The majority of caregivers in the sample reported having access to a primary doctor for their child when in need of routine health care. The caregivers were most likely to report difficulties with obtaining specialized services, specifically speech, physical therapy, occupational therapy, and dental care. Caregivers reported that cost of services was the primary factor, followed by eligibility. Even when covered, out-of-pocket costs for families can exceed what many are able to afford. As such, it is critical that families receive quality therapy in the limited number of sessions available to them in order to get the most out of the services they are able to receive.

A quarter of caregivers reported having to reduce work hours, another 18% left their jobs and, 16% reported not being able to leave their job because of insurance concerns. It is important to consider that families with more financial resources at their disposal have a greater ability to allow a caregiver to reduce work hours or to leave a job altogether. This may not be an option for families that require two incomes to make ends meet, or for single parent households.

Community-based Services and Supports

Pediatricians, family and friends, and other parents were reported by caregivers as important sources of information and support. Support groups, whether in the community or at the child's school were cited as critical sources of information and emotional support for parents and were highly valued. According to the data, parents value the opportunity to interact with other parents and see them as important sources of information. Equipping pediatricians with information to enable them to refer parents to support groups and services is another avenue to connect parents and caregivers to this supportive resource. Caregivers also report reaching out to their child's school to receive important information, but almost half of the sample reported not receiving enough information about their child's special needs from their school.

Care Coordination and Family-service Provider Partnerships

Caregivers reported having difficulty understanding how the special needs system works. Many experts pointed out that parents often aren't aware of available services. Regardless of parents' experience with the system, the amount of time and resources it takes to find anything out is challenging to most parents. Experts agreed that improved system integration is needed. The community needs to work on a seamless, continuum of services which includes universally accepted assessment tools and diagnostic criteria, ongoing progress assessments, and transition into adulthood planning.

Less than a quarter of caregivers reported using case managers and advocacy services, but those who have used these services are highly satisfied with them. Many caregivers would benefit from receiving more information from their school site, as they look to the schools as one of their primary sources of information. Experts commented that the collaboration with the school system is challenging and the root of that is likely capacity; schools are overburdened.

Transition Support

Transition support needs to be improved at all levels. With regard to transition to adulthood, the majority of parents reported they did not receive services that are currently available. It is unclear if this represents a problem of capacity, or an awareness issue, or both. Help is needed to prepare parents and children for transitions to adulthood. This includes, but is not limited to, financial and guardianship planning, employment, and independence planning.

Customer Experience

Overall, parents are highly satisfied with community service provider quality and treatment. Barriers exist for about 20 to 30% of families with regard to hours and locations. No ethnic or racial disparities with respect to service satisfaction were identified. Most parents report being satisfied with their Individualized Education Programs (IEP), communication from the school regarding progress, and understand what they are being told by school personnel. Only half of parents reported that school provided them with information about additional support, and most reported that the schools don't offer them additional training. So, while parents aren't receiving as much information from the schools as they would like, they are for the most part satisfied with what they do receive.

Service Disparities

Caregivers were mostly satisfied with the cultural responsiveness of service providers. That being said, 1 in 10 families agreed with statements indicating that they have faced discrimination based on race, ethnicity, or the language they spoke. Caregivers of Black children were more likely to agree that they faced discrimination. This suggests that more training is needed for providers with regard to racial or ethnic discrimination.

■ INTRODUCTION

On behalf of the Special Needs Advisory Coalition (SNAC), Children’s Services Council of Broward County (CSC), Broward County Children’s Services Administration, United Way of Broward County, and Broward Behavioral Health Coalition contracted with Q-Q Research Consultants (Q-Q Research) to design and implement an assessment of the current service delivery system serving children and youth with special needs in Broward County, Florida. Special needs categories included intellectual, developmental, physical, specific learning disabilities, and/or behavioral health concerns. Ultimately, this strategic Special Needs System of Care Assessment (SN SOCA) aims to shape decision making to improve the service delivery system, program implementation, and outcomes for children and youth with special needs in Broward County. This assessment also sought to provide information leading to the improvement of policies related to the well-being of children and youth with special needs. Of special interest and importance is the examination of the intersection of race and ethnicity with disabilities.

Racial disparities in special needs services have been well documented in the research literature. Students of color in the United States have repeatedly been reported to be over-identified as disabled and thus disproportionately overrepresented in special education.¹ Unfortunately, placement in special education does not always ensure adequate or quality services by race or ethnicity.² Research indicates that White school-aged children generally receive higher quality services in special education when compared to students of color. Moreover, students of color are overrepresented in less rigorous special needs programs and demonstrate far worse outcomes when compared to their White peers.³ As such, it is of interest to explore whether there are any racial and ethnic disparities as it relates to access of special needs services and the service experiences of families in Broward County.

This assessment was conducted to achieve the following general objectives:

- 1) Identify probable unmet service needs and gaps within the special needs system of care in Broward County with a focus on potential racial or ethnic disparities,
- 2) Identify possible community assets and resources, and
- 3) Provide findings that will allow stakeholders to develop priorities and strategies to address the identified needs and gaps while utilizing and mobilizing existing community resources.

Q-Q Research has prepared this report as a summarization of the desired objectives described above. The ultimate goal is to help SNAC determine the needs of children with special needs and their families and to make data-driven decisions regarding gaps in services and disparate service utilization. Results from this assessment can be used to develop strategies to assist children and youth with special needs and their families in Broward County, and aid future decision making related to resource allocation.

About the Data

A significant portion of the data in this report comes from the Caregiver of Youth with Special Needs Survey (CYSNS). The CYSNS was developed by Q-Q Research and its research team in consultation with the CSC of Broward County, along with a variety of stakeholders. The CYSNS was administered to examine the perceptions of caregivers of youth with special needs who receive services in Broward County. Additionally, qualitative data was captured from nine focus groups attended by parents, experts, and youth transitioning out of high school, facilitated by the research team. Supplementary data sources were included as well, through the review and synthesis of publicly available state and county level data. Preliminary results were presented to SNAC in a focus group format for feedback and recommendations prior to final analyses. For ease of reading, the source and year are included in the text when the time frame is necessary for understanding the data. Additionally, data was rounded to improve readability. After a thorough review of all available data

sources through various analytic approaches, it was noted that in general, findings were consistent across informants and sources. When multiple data sources from varied approaches yield similar results, confidence in the accuracy and strength of the findings is increased.⁴

Assessment Methodology

In order to meet the key objectives of this SN SOC assessment, a comprehensive mixed methods design was adopted utilizing methods to collect qualitative and quantitative data. Quantitative data was captured from the CYSNS. Qualitative data was obtained from focus groups facilitated by the research team. In addition to this, a series of secondary data sources were analyzed in order to leverage existing information. The procedures and methodology employed for data collection using each assessment method are described in Appendix A.

I Survey Development and Administration

In an effort to gather caregivers' perceptions using a quantitative approach, the research team developed the CYSNS that aimed to gather perceptions on several factors including, but not limited to, caregiver experience with access to services, gaps in services, transition support services, and referral support services. This survey also captured demographic information such as race and ethnicity so that analyses to examine potential racial and ethnic disparities could be conducted.

The research team developed the CYSNS using structured questions that aimed to gather caregiver perceptions on several factors to quantify caregiver attitudes, perceptions, and satisfaction with services provided to their child with special needs. The research team identified the following content domains for inclusion in the survey:

- 1) Special need identification, screening, assessment, and referral
- 2) Access to care
- 3) Community-based services and supports
- 4) Care coordination
- 5) Transition support
- 6) Customer experience, and
- 7) Family-service provider partnerships

Specific details regarding survey development can be found in Appendix B.

The final approved CYSNS was made available to several providers of services for children with special needs in Broward County identified by CSC. In an effort to obtain a diverse sample, the survey was made available online and advertised to caregivers through community partners.

In total, 1,469 surveys were collected from caregivers of children and youth who live and receive services in Broward County. Participants came from a variety of backgrounds. Of these respondents, 853 caregivers reported that their child had been diagnosed with a disability or a special need. Sixteen percent (16%) of the sample chose not to answer questions on the sex, race and ethnicity of their child. The demographic information that follows represents the demographics of the youth whose caregiver identified that he/she had been diagnosed with a special need and provided demographic information (n = 853).

The majority of the participants who provided race or ethnicity information identified their child as White (54%), or Black (31%), and non-Hispanic (63%). Other self-reported races included Asian and Native American. Seventy-three percent (73%) of respondents who reported the sex of their child with special needs were caregivers of male, while 27% were caregivers to females with special needs. The average age of the caregiver’s child with special needs was 10 years.

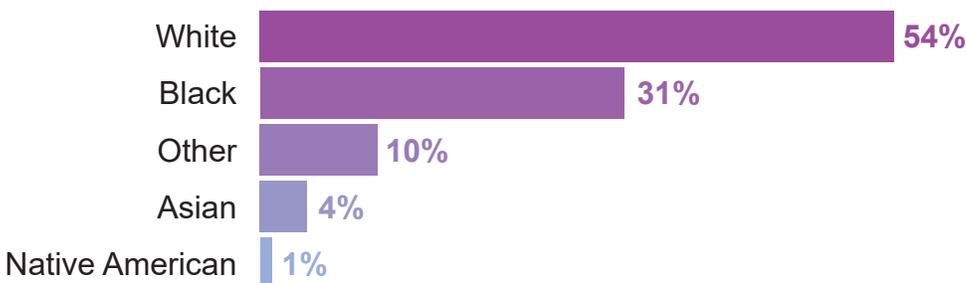
Figure 1. Child Gender Distribution



Figure 2. Child Ethnicity Distribution



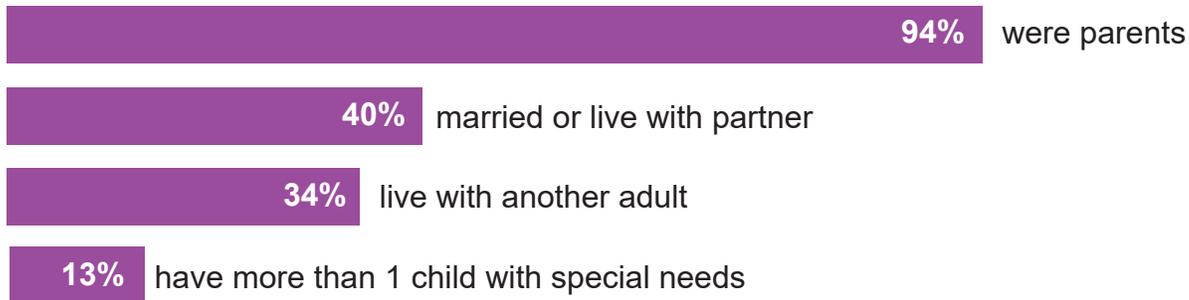
Figure 3. Child Race Distribution



Participants lived in 66 different zip codes, mostly in Broward County, and a few participants lived in Miami-Dade or Palm Beach Counties. It is likely that these families receive services from Broward County providers and live close to the county line. The most commonly reported zip codes were 33023, 33024, 33313, 33071, 33324, 33328, 33021, 33065, 33068, 33311, 33076, 33322, 33351, 33025, and 33321.

With regard to the caregivers themselves, of those who answered questions regarding their own personal characteristics, 94% of the respondents identified themselves as parents of a child. Thirteen percent (13%) of caregivers indicated that they had more than one child with a special need. Only 40% of the caregivers reported being married or living with a partner, and 34% reported living with another adult.

Figure 4. Caregiver Descriptors



Ninety percent (90%) of caregivers were female, and the majority were between the ages of 36-45 (47%) or 26-35 years of age (17%).

Figure 5. Caregiver Gender Distribution

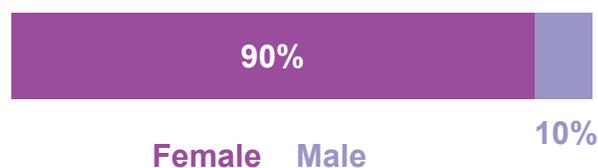
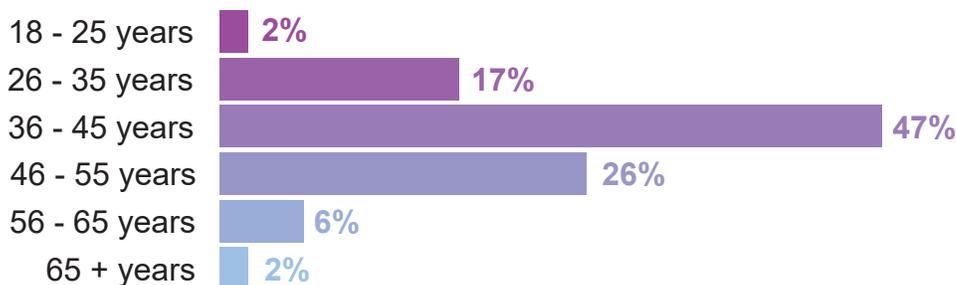


Figure 6. Caregiver Age Distribution



The majority of the caregiver participants who provided race/ethnicity information identified as White (58%) and Non-Hispanic/Latino (69%). Self-reported races included Asian and Native American. Most respondents (93%) indicated that they spoke English at home.

Figure 7. Caregiver Race Distribution

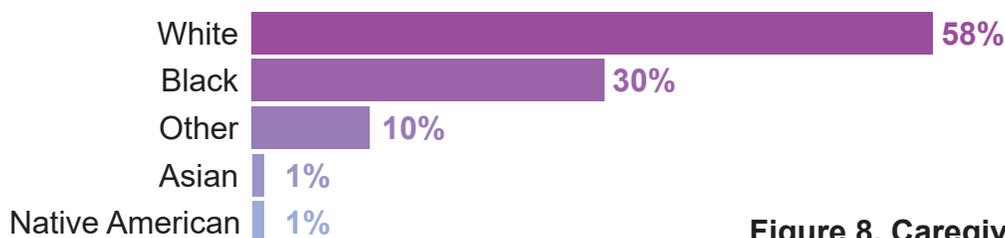


Figure 8. Caregiver Ethnicity Distribution



Table 1. Languages Spoken at Home

| Languages Spoken at Home | N | Percent | Percent of Cases |
|--------------------------|-----|---------|------------------|
| English | 498 | 75.3% | 93.3% |
| Spanish | 120 | 18.2% | 22.5% |
| Creole | 18 | 2.7% | 3.4% |
| Other | 25 | 3.8% | 4.7% |

Caregivers came from a variety of economic backgrounds, with the most commonly reported income bracket being between \$25,000 and \$49,999. Twenty-six percent (26%) of the sample reported receiving Social Security benefits for their child, while 63% reported that they did not receive benefits.

Figure 9. Caregiver Annual Income Distribution

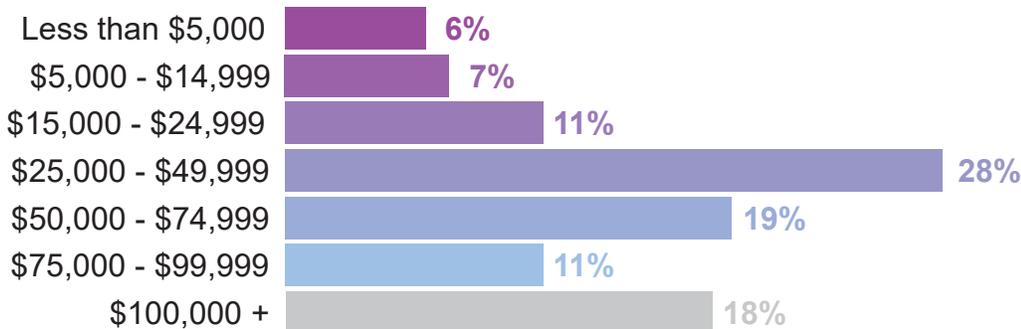


Figure 10. Caregiver Employment Status Distribution



■ Assessment Findings and Community Perceptions

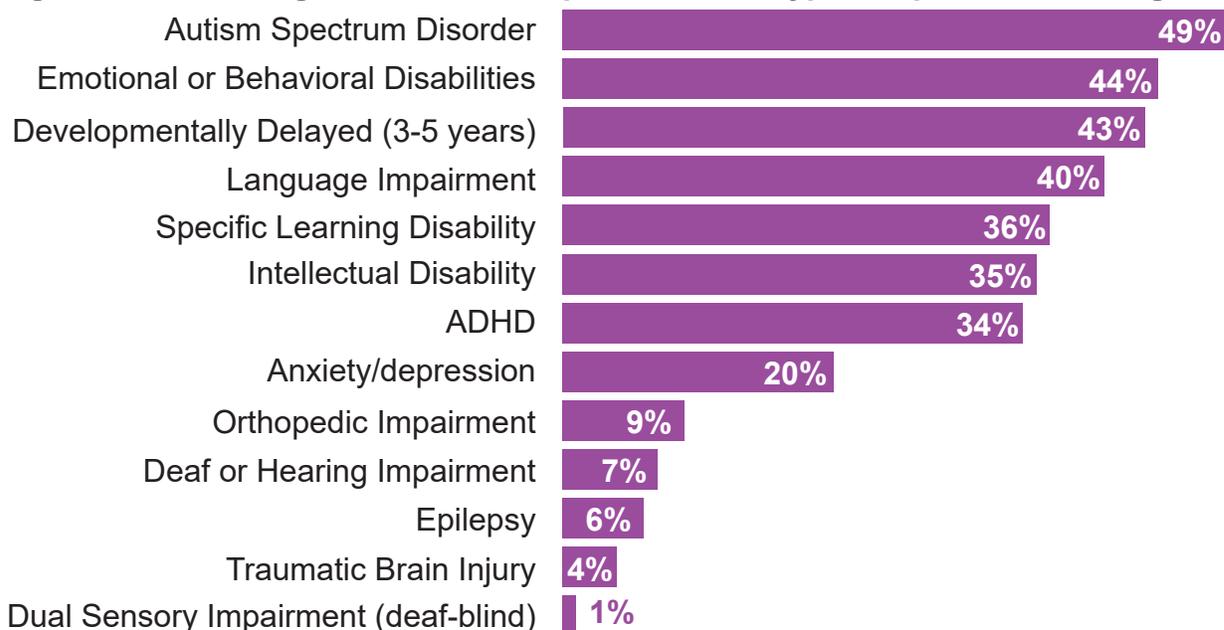
The Assessment Findings and Community Perceptions section presents the findings of the SN SOCA organized into seven subsections (Screening and Referral of Youth with Special Needs, Access to Care, Community Based Services and Supports, Care Coordination and Family/Service-Provider Partnerships, Transition Support, Customer Experience, and Service Disparities). The findings are organized by data source under each subcategory. Findings from the CYSNS survey are presented under the headings CYSNS Survey Findings: Caregiver Perceptions. It is important to note that the results presented in the sections labeled CYSNS Survey Findings represent the perceptions of caregivers who reported that their child had received a special needs diagnosis. Perceptions of caregivers who reported that their child had not received a diagnosis are reported in Appendix D. Findings from the focus groups are under the heading *Focus Group Findings*, which is further broken down into *Caregiver Perceptions* and *Expert Opinions*. Finally, each primary section ends with *Key Points and Recommendations* to help the reader draw conclusions from the data.

1. Screening and Referral of Children and Youth with Special Needs

CYSNS Survey Findings: Caregiver Perceptions

Caregivers were asked to respond to a series of questions related to the identification and screening of their child with special needs. In order to learn more about the children with special needs in our sample, the caregivers were asked to provide the type of special need with which their child had been diagnosed, along with the age at which the child was diagnosed with a special need, and which type of professional provided their child a diagnosis. Caregivers could select multiple diagnoses if their child had been diagnosed with more than one disability. The most common diagnoses for children in our survey sample were Autism Spectrum Disorder (ASD, 49%), followed by Emotional and Behavioral Disabilities (EBD, 44%), Developmentally Delayed (43%) and Language Impaired (40%). The next most common diagnoses were Specific Learning Disabilities (SLD, 36%), Attention Deficit Hyperactivity Disorder (ADHD, 35%), and Intellectual Disabilities (ID, 34%). Approximately 20% of the sample had a diagnosis of anxiety or depression, and less than 10% of the sample were diagnosed with orthopedic impairments, hearing and/or visually impaired, epilepsy, or a traumatic brain injury (TBI) (see Figure 11).

Figure 11. Percentage of CYSNS Sample with Each Type of Special Need Diagnosis



SOURCE: CYSNS Survey, Q-Q Research, 2018



Table 2 lists the average age of diagnosis by type of special need for the children in our sample ranked in ascending order by age. Major physical impairments, along with developmental delays and language impairments on average were diagnosed around 3 years of age. ASD, Epilepsy, ID, SLD, and EBD on average were diagnosed around the time the children were ages 4 to 5, coinciding with entry to school/pre-school. Nationally, Autism is typically diagnosed at age 4⁵, ADHD at age 7⁶, and child anxiety between 4 and 8 years of age⁷, which is for the most part consistent with the reported ages of diagnoses in our sample. There were no significant differences in age of diagnosis within special need for this sample with respect to sex of child, race, or ethnicity.

Table 2. CYSNS Sample: Average Age of Diagnosis by Special Need Type

| Diagnosis | Sample N | Age at Diagnosis in Years | |
|--------------------------------------|----------|---------------------------|-------|
| | | M | (SD) |
| Anxiety/Depression | 170 | 8.23 | -3.92 |
| ADHD | 293 | 6.28 | -2.67 |
| Emotional or Behavioral Disabilities | 379 | 5.14 | -3.08 |
| Specific Learning Disabilities | 304 | 4.89 | -3.11 |
| Intellectual Disabilities | 295 | 4.76 | -3.4 |
| Epilepsy | 51 | 4.02 | -4.3 |
| Autism Spectrum Disorder | 419 | 3.95 | -2.55 |
| Language Impairment | 343 | 3.31 | -2.51 |
| Deaf or Hard of Hearing | 60 | 3.2 | -3.4 |
| Orthopedic Impairment | 76 | 2.58 | -2.78 |
| Traumatic Brain Injury | 30 | 2.52 | -4.58 |
| Developmentally Delayed (3-5 years) | 370 | 2.46 | -2.39 |
| Dual Sensory Impaired (Deaf-Blind) | 12 | 1.38 | -1.92 |

SOURCE: CYSNS Survey, Q-Q Research, 2018

We also asked caregivers to specify which type of provider diagnosed their child with a special need disability. Table 3 provides a summary of the types of provider that diagnosed the children in the current sample for the 8 most commonly reported diagnoses. Caregivers reported that their children were most commonly diagnosed by a specialist, with the exception of Anxiety/Depression, which was most commonly diagnosed by a psychiatrist.

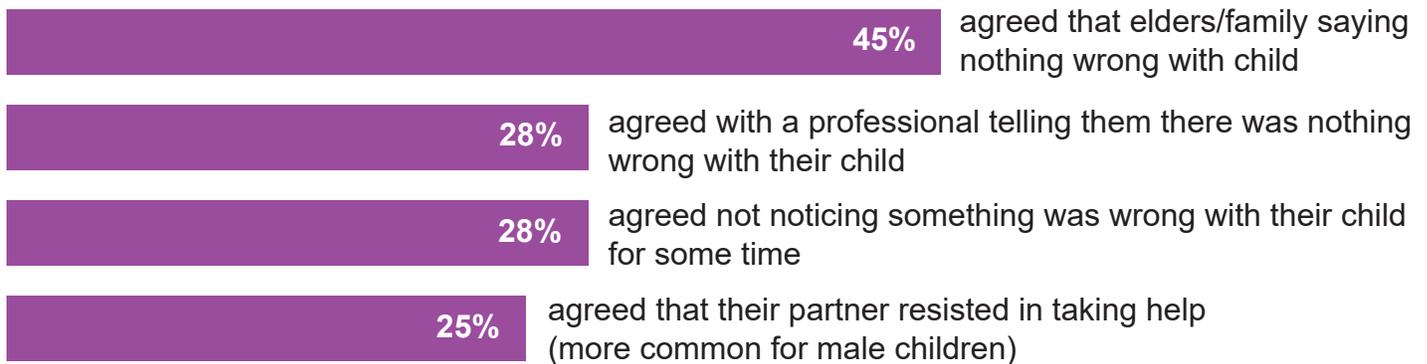
Table 3. Type of Provider that Diagnosed Your Child with a Special Need (percent)

| Provider Type | Autism | Developmental Delay | Emotional/ Behavioral | Language Impaired | Specific Learning | Intellectual Disability | ADHD | Anxiety/ Depression |
|--------------------------------|--------|---------------------|-----------------------|-------------------|-------------------|-------------------------|------|---------------------|
| Specialist | 55.6 | 45.8 | 33.5 | 49.4 | 34.1 | 37.3 | 30.3 | 25.4 |
| School Psychologist/ Counselor | 14.7 | 8.9 | 13.9 | 13.3 | 32.1 | 19.2 | 8.3 | 7.1 |
| Primary Care Provider/Doctor | 10.7 | 21.2 | 18.6 | 17.9 | 17.6 | 18.1 | 21 | 13 |
| Other Psychologist | 7.2 | 3.9 | 9.1 | 2.7 | 4.4 | 9.4 | 16.6 | 13.6 |
| Other | 4.7 | 10.1 | 7.5 | 10.9 | 6.4 | 7.7 | 4.5 | 4.7 |
| Psychiatrist | 4 | 1.7 | 13.9 | 0.6 | 2 | 4.2 | 17.2 | 32.5 |
| Social Service Agency | 3 | 8.4 | 3.6 | 5.2 | 3.4 | 4.2 | 2.1 | 3.6 |

SOURCE: CYSNS Survey, Q-Q Research, 2018

In addition, caregivers were asked to agree or disagree with a series of statements related to their experiences and knowledge around the identification and screening of special needs issues. Many caregivers agreed that either a professional (28%) or a family member or elder (45%) told them that nothing was wrong with their child. About 28% agreed they did not notice anything was wrong with their child for quite some time. Additionally, 25% of caregivers stated their partner resisted taking their child for help; caregivers of male children with special needs were significantly more likely to agree that their partner resisted taking their son for help (see Figure 12). No other racial or ethnic disparities were identified with respect to agreement on these statements.

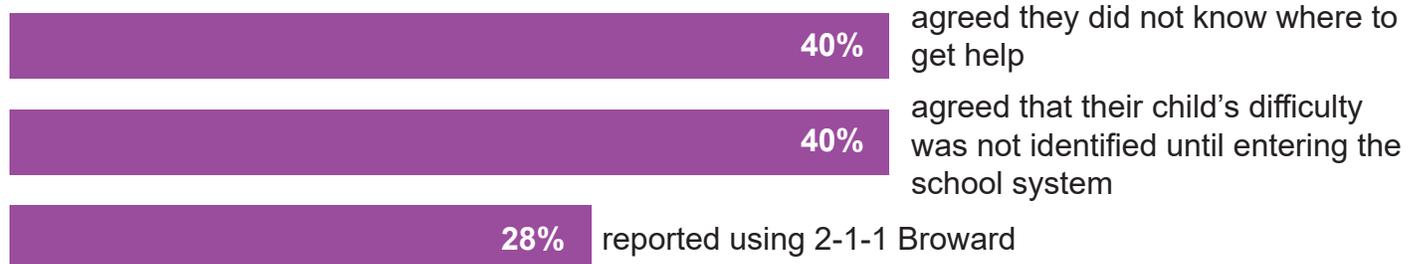
Figure 12: Caregiver Responses to CYSNS Questions: Special Need Screening



SOURCE: CYSNS Survey, Q-Q Research, 2018

Approximately 40% of caregivers agreed initially that they did not know where to go for help. In addition, 40% of caregivers agreed that their child’s difficulty was not identified until entering the school system. Finally, only 28% of caregivers reported using 2-1-1 Broward to obtain information for their child with special needs indicating only a small percentage of families to obtained information about available resources from 2-1-1 Broward.

Figure 13: Caregiver Responses to CYSNS Questions: Special Need Screening



SOURCE: CYSNS Survey, Q-Q Research, 2018

Finally, caregivers were asked if their child with special needs ever had an Individualized Education Program (IEP) or Individualized Family Service Plan (IFSP). The majority of caregivers, 85%, reported that their child had an IEP. In addition, we asked caregivers to report the age of their child upon first receiving their IEP or IFSP. On average, youth in our sample received their first IEP at 4.79 years of age (SD = 2.67). In addition, 83% of caregivers reported that their child is currently receiving services. While 15% of caregivers responded that their child has never received an IEP or IFSP, it is not possible to determine if their children ever had an IEP, or if the caregivers were simply unaware that an IEP was in place. Finally, in the current sample, the caregivers of Hispanic children reported that their child received an IEP at a significantly younger age (4.43 years) than the caregivers of non-Hispanic children (5.03 years). No other differences were found with respect to sex of child, race or ethnicity. It is important to note these data represent caregiver report of age of first IEP and the accuracy of the data is dependent upon their recollection.

Figure 14: Caregiver responses to CYSNS Questions: IEP/IFSP



SOURCE: CYSNS Survey, Q-Q Research, 2018

Focus Group Findings

Caregiver Perceptions

A series of questions were asked to parents of children with special needs about their experiences with the special needs system of care around the time of identification and screening. Caregivers were asked what they would most need to know about their immediate future and about the types of information and supports they had received at the time of screening or diagnosis.

Family needs around the diagnosis time varied depending on when the diagnosis was received. However, most parents agreed that the primary need at this time was to understand the immediate and long-term implications of the diagnosis for their child and family. Next, caregivers indicated that they began asking questions about services their child would need including: availability, location, eligibility, cost, insurance coverage, etc. For those with school-age children, a diagnosis raised questions about inclusion (e.g., “Are they going to be removed from the classroom?”) and the transition from general education to special education (e.g., “What is an IEP or a 504 plan?”).

When asked what would have been helpful as a resource during this time, caregivers indicated they would have liked to have access to a “one-stop shop resource directory” and would prefer it to be web-based.

“There should be a place or a resource where you could go and get the majority of your questions answered based off of your child’s need.”

“A website, where you can put in all the criteria, and then it gives you the roadmap of these are the things that are there, these are the steps that you have to take.”

Expert Opinions

Similar questions were posed to experts regarding family needs at the time of identification and screening. According to experts, a significant need for families during screening and identification is a quick and accurate diagnosis. Parents' lack of knowledge of when a diagnosis is needed, along with how and where to get a diagnosis, is a major obstacle to the child starting services in a timely manner. Many parents are not aware of the 2-1-1 Broward service.

Experts spoke about Early Steps, the federal entitlement program under Individuals with Disabilities Education Act (IDEA) that assists in identifying needs of children ages birth - 3. Early intervention services are available throughout the state and do not require a diagnosis. Experts stated that Early Steps does extensive outreach to recruit eligible families in the community (e.g., resource fairs, pediatrician outreach). In addition, Early Steps conducts screenings in partnership with five NICUs (Newborn Intensive Care Units). In total, it is estimated that Early Steps processed approximately 4,000 referrals for Broward County in one year.

Expert focus group participants also pointed to the work of the Early Learning Coalition (ELC) in educating pre-school staff and parents about the importance of referring children to Early Steps for early diagnosis. Often times, experts commented that caregivers refused evaluations because they did not want their children labeled. ELC provides opportunities for teachers to learn from inclusion specialists through in-classroom services and training.

Furthermore, experts discussed Child Find, which assists in locating, identifying and obtaining services for children with disabilities or special needs under the Florida Diagnostic and Learning Resource System (FDLRS) and Broward County Public Schools (BCPS).

Representatives of the provider community agreed that Child Find has done a good job educating pediatricians and neurologists and bridging the gap between the medical community and health and human services providers. In addition, Help Me Grow goes out to different pediatric offices to ensure doctors and staff are trained on early identification and how to make appropriate referrals. However, experts stated that not all physicians are committed to going beyond issuing a diagnosis.

Among the barriers identified, experts noted that Child Find has a four-month waiting list to begin the evaluations necessary for entry into the 3-5 pre-K Exceptional Student Education (ESE) program. Experts noted that they have worked hard to advocate that the school board have enough assessment teams to evaluate kids in a timely manner, but delays are caused by increased demand, along with staffing and budget issues.



Still, experts spoke of a culture of collaboration in Broward County that assists with the referral process. One example of creative partnerships around the time of diagnosis is the arrangement between the Center for Hearing and Communication (CHC) and the Dan Marino Pediatric Outpatient Center in Weston. The organizations agreed to have CHC social workers available during clinic days so that any neurologist diagnosing new children can make an immediate referral.

Finally, experts pointed out that children with co-morbidities or dual diagnoses present challenges with the diagnosing process.

Key Points and Recommendations

Early screening and diagnosis are essential for children and youth with special needs to receive early intervention. In the current sample, a little more than a quarter of caregivers reported not noticing anything was wrong for quite some time. Almost half of caregivers reported that extended family/elders told them that there was nothing wrong with the child and a quarter of caregivers reported resistance from their partner in seeking help. The majority of caregivers reported being diagnosed by a specialist or Primary Care Physician. Pediatricians may be in the best position to help with early identification and referral.

Increasing parental and family awareness of early signs of special needs is a key factor in getting these children and youth the assistance necessary to be successful. All family members (mothers, fathers, and grandparents) need to be reached in awareness campaigns, which should be culturally responsive to the respective communities.

Exploring policy changes and enhancing existing collaborations at the state and local levels could improve screening and early access to services. For example, the South Carolina Act Early Team (SCAET) coordinated a partnership among various agencies, including the state, universities, health care systems, and other private organizations to address access to services for children with ASD.⁸ The collaboration led to policy changes, trainings for providers, and transformed agency practices. Providers implemented a 2-tiered screening process for children 0-3, that established presumptive eligibility for services. According to a recent study, the changes led to a 500% increase in children eligible for early intensive behavioral intervention (EIBI). In addition, only 2.5% of the children presumed eligible were later established not to have ASD.

A local public health campaign, similar to the CDC's "Learn the Signs, Act Early" campaign,⁹ could assist caregivers in early identification of potential problems and what to do if they were concerned. A recent study of caregivers' experiences and needs during the identification phase of developmental delay found that if caregivers were aware of a concern, they often discussed these issues with a primary health care provider. Their research indicated that, for the campaign to be most effective, it would be important to teach caregivers not only to learn the signs of a delay, but also to help them understand why acting early was of the utmost importance.¹⁰

About 40% of caregivers reported not knowing where to get help at the time of screening and diagnosis. Only a little more than a quarter of caregivers reported using the 2-1-1 Broward service to obtain information regarding assistance for their child with special needs. In addition, caregivers requested an improved online resource to access needed information. While www.211specialneeds.org exists, caregivers are either not aware of the resource or do not seem to find the resource adequate to meet their needs or user friendly.

Structuring a dedicated special needs website like 211specialneeds.org in a way that is either easier to navigate or provides more types of information may be beneficial. Experts and caregivers recommended that a comprehensive and up-to-date resource guide, preferably web-based should be readily available. Ideally, caregivers and experts thought the guide should include information on services for all types of special needs and disabilities, and include information regarding a variety of resources (e.g., obtaining a Medicaid Waiver, advocacy resources, lawyers specializing in special education, and tax advice). Their recommendations were that the guide should be disseminated through a variety of avenues (e.g., school, health and other providers). Social media could be leveraged to increase awareness of existing resources.

One example of a user-friendly website that addresses some of the above concerns is the Southwest Florida Resource Link (e.g., <http://www.swflresourcelink.com>). The drop down menu on the front of the aforementioned page might be helpful in getting parents and caregivers information they need more easily. The investment of resources in designing a more user-friendly website that comes up first in searches when caregivers use search engines to look for resources could positively impact early screening. Marketing campaigns that increase user access to these platforms would also be needed.

The only disparity identified with respect to caregiver perceptions regarding screening and diagnosis dealt with caregivers of boys with special needs being more likely to agree with their partner resisting getting help. Potentially, a difference in help-seeking behaviors of caregivers may exist depending upon the sex of their child. This may be related to cultural norms, and the expectations that caregivers have related to the development of boys versus girls.

Providers responsible for screening and diagnosis could benefit from trainings that focus on the multiple sociocultural values and beliefs that influence parent help-seeking behaviors.¹¹

2. Access to Care

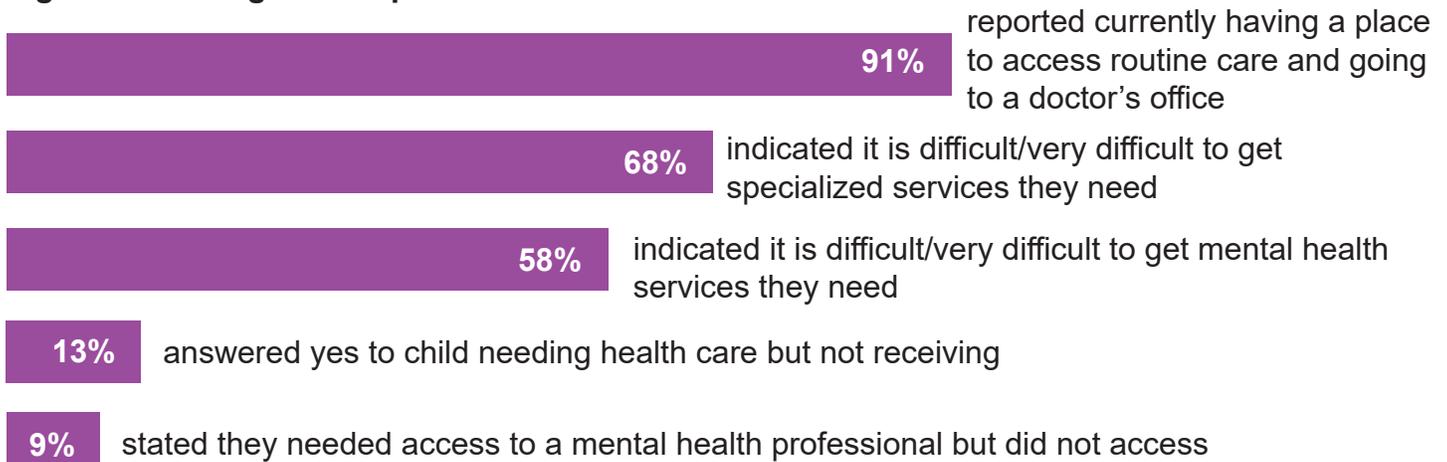
CYSNS Survey Findings: Caregiver Perceptions

Caregivers were also asked to respond to a series of questions related to access to care and barriers they may face in receiving needed services. The majority of caregivers (91%) reported they do indeed have a place to take their child to access routine health care. About 60% of caregivers reported that at some point during the last 12 months, a provider did ask them if they were concerned about their child's learning, development or behavior. Thirteen percent (13%) of caregivers reported needing access to health care for their child but were not receiving it. At the same time, a large percentage of caregivers (68%) agreed that it was difficult or very difficult to get the specialized services needed for their child.

Regarding behavioral and mental health services, 32% of caregivers reported receiving treatment for their child from a mental health professional; 59% reported not needing this type of service for their child. About 30% of caregivers reported that their child received behavioral intervention services for a developmental delay (i.e., Autism, ASD, Asperger's, ADD). Roughly 28% of caregivers reported that their child received services for a diagnosis of ADHD, with 23% reporting that their child also received medication for ADHD. Similarly, 21% of caregivers reported that their child received services for a diagnosis of anxiety and/or depression, with 23% reporting that their child also received medication for anxiety and/or depression.

Nonetheless, more than half (58%) of caregivers agreed that it was difficult or very difficult to receive mental health care and about 9% stated their child needed access to a mental health professional but did not receive it. Next, caregivers were asked if their child received any specialized services outside of the school day; around 43% of caregivers indicated that their child did indeed receive services outside of the school day.

Figure 15: Caregiver Responses to CYSNS Questions: Access to Care



SOURCE: CYSNS Survey, Q-Q Research, 2018

Access to Services for Developmental Delay: Caregivers of Hispanic children were significantly more likely to report receiving treatment for their child than caregivers of non-Hispanic children. Caregivers of White children were significantly more likely to report receiving treatment for their child than caregivers of non-White children. Finally, caregivers of Black children were significantly less likely to report receiving treatment for their child than caregivers of non-Black children.

Access to Services for ADHD: Caregivers of boys were significantly more likely to report receiving both behavioral treatment and medication for their children than caregivers of girls. Furthermore, caregivers of White children were significantly more likely to report receiving ADHD medication for their child than caregivers of non-White children.

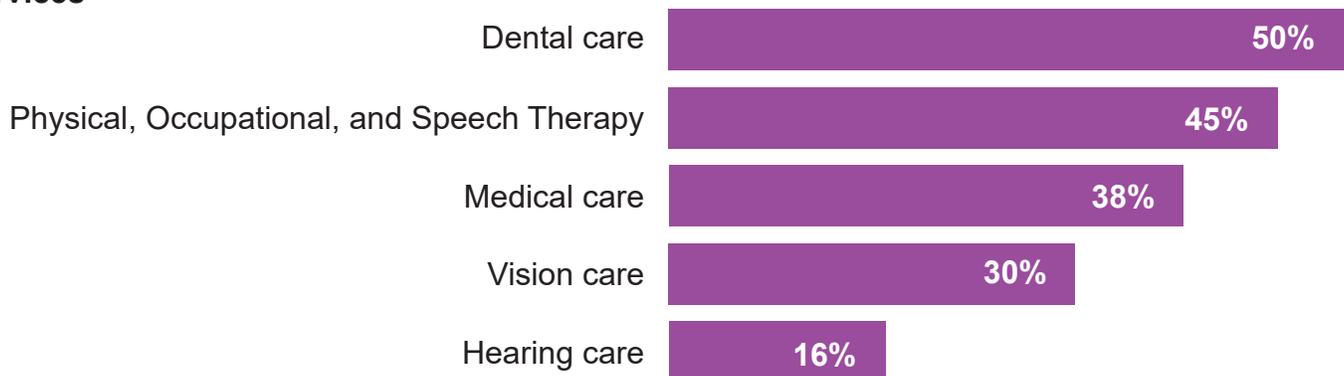
Access to Services for Anxiety and Depression: Caregivers of White children were significantly more likely to report receiving both behavioral treatment and medication than caregivers of non-White children. Moreover, caregivers of Black children were significantly less likely to report receiving both behavioral treatment and medication for their child with anxiety and depression than caregivers of non-Black children. Finally, caregivers of Hispanic children were significantly less likely to report receiving anxiety/depression medication for their child than caregivers of non-Hispanic children.

Access to Specialized Services: Caregivers of Hispanic children were significantly more likely to report receiving specialized services outside of the school day than caregivers of non-Hispanic children. Likewise, caregivers of White children were significantly more likely to report receiving specialized services outside of the school day than caregivers of non-White children.

Regarding the ease of access, caregivers of boys were significantly more likely to report it was difficult to access specialized services than caregivers of girls. Similarly, caregivers of White children were significantly more likely to report it was difficult to access specialized services than caregivers of non-White children. Finally, caregivers of Hispanic children reported it was significantly more difficult to access mental health services than caregivers of non-Hispanic children, while caregivers of Black children reported it was significantly less difficult to access mental health services than caregivers of non-Black children.

Barriers to Accessing Services: Next, caregivers were asked to answer questions about various barriers to accessing services for their child with special needs. When asked about which types of services were difficult to access, parents reported the most difficulty with receiving Dental care (50%) followed by Physical Therapy (PT), Occupational Therapy (OT), and Speech Therapy, Medical Care, Vision Care, and Hearing Care. There were no differences in responses of caregivers by sex of child, race or ethnicity.

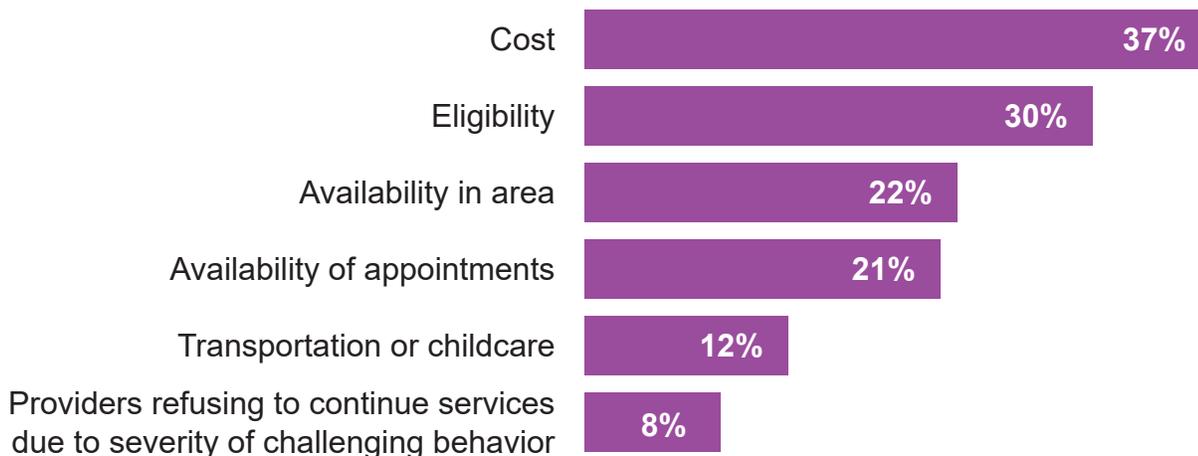
Figure 16: Caregiver Responses to CYSNS Questions: Difficulty Accessing Specialized Services



SOURCE: CYSNS Survey, Q-Q Research, 2018

Next, caregivers were asked to answer questions about various barriers to accessing services for their child with special needs. The most common reasons reported by caregivers for not receiving services were related to cost (37%) and eligibility (30%). Additionally, caregivers reported access issues related to lack of service availability in their area (22%), availability of appointments (21%), transportation or child care issues (12%), and providers refusing to continue services due to severity of challenging behavior (8%). There were no differences in responses of caregivers by sex of child, race or ethnicity.

Figure 17: Caregiver Responses to CYSNS Questions: Barriers to Receiving Specialized Services



SOURCE: CYSNS Survey, Q-Q Research, 2018

Finally, participants were asked about employment related difficulties they have experienced related to their child's special need. While a little more than half of the participants reported no work-related difficulties, approximately 28% reported having to reduce work hours to ensure their child with special needs received services. Moreover, 18% reported having left their job or having taken a leave of absence to manage their child's special need. Finally, 16% of caregivers reported that they avoided changing jobs to maintain their insurance. Caregivers of White children were significantly more likely to report reducing work hours and avoiding changing jobs than caregivers of non-White children.

Focus Group Findings

Caregiver Perceptions

A series of questions were asked of caregivers about barriers and difficulties they have faced with accessing the services needed by their child. The primary challenges described by focus group parents were difficulties related to financial burdens of care, service eligibility, and insurance coverage. Numerous comments depicted parents' concerns about the Medicaid system, including lack of eligibility for Medicaid, insufficient number of service providers taking on new Medicaid patients and long waiting lists for Medicaid and associated waivers.

"I would love to provide him OT (Occupational Therapy), speech, any of that, but I'm not on Medicaid and my insurance doesn't cover this stuff. I'm in that dead zone."

In the absence of Medicaid, obtaining private insurance for services is not easy.

“Insurance doesn’t cover special need behavior services. ABA (Applied Behavior Analysis) is a tough one.”

“We’ve been approved for residential treatment. However, my insurance, my personal, private insurance won’t cover it.”

Even when financial supports are available, caregivers indicated that supports are hardly enough to cover ongoing needs.

“My son’s scholarship lasted him a month and a half worth of speech. He needs it 2 or 3 times a week for the rest of his life.”

Parents also commented on barriers related to timing and location of services offered for youth, especially for working parents.

“Agencies tend to put things in places where it’s economically disadvantaged places. Autism is across the board. I would really like to see agencies put things throughout the county.”

“When you’re a single parent and you’re working full time, you can’t leave in the middle of the day to take them and pick them up.”

Expert Opinions

Providers agree with parents in that challenges related to Medicaid coverage and services are at the top of the providers’ list. Among the most common concerns are the following:

- 1) Medicaid’s differential coverage depending on the type of disability;
- 2) Waiting list for Medicaid Waiver in Florida for residential treatment;

“There is a 21,000-person waiting list in the state of Florida to get on that waiver.”

- 3) Medicaid Moratorium or Lack of Medicaid providers;
- 4) Medicaid gaps for older youth with disabilities;
- 5) Medicaid donut hole or loss of benefits due to increased income;

“She went to Medicaid, and they said: “Well yeah, you should either quit your job or get divorced.”

Outside of Medicaid, private insurance coverage involves many challenges. According to providers, counterproductive policies are often implemented. For example, some insurance companies restrict services once a child's behavior improves.

Experts remarked that lack of eligibility consistency across various funding streams is another big challenge. County, state and federal guidelines do not match, and providers may be faced with multiple criteria just to meet their funders' requirements. Discretionary, short-term funding with no guarantee of continuation compounds the problem for providers. Federal funding for the Medicaid Waiver program organized by the state has been limited to the point that no new cases can be added to the waiting list unless there is a crisis. Long waiting lists are also a challenge for workforce services for people with disabilities.

Key Points and Recommendations

The majority of caregivers in our sample reported having access to a primary doctor for their child when in need of routine health care. As many of these families seem to report access to a doctor, this furthers the notion that if primary care providers facilitate conversations, make referrals, and provide information about community-based services and supports, they could potentially reach the majority of families. This would require not only educating health care providers about the system of care, but a willingness on their part to engage with families in these conversations.

The caregivers in our sample were most likely to report difficulties with obtaining specialized services, specifically Speech, PT, OT and dental care. Caregivers reported that cost of services was the primary factor, followed by eligibility.

Regarding to Speech, PT and OT, research has shown that children from families with higher incomes are more likely to receive these types of services. It could be that these families have additional resources that better allow them to not only afford the cost of services, but that also make it easier for them to adhere to a plan of care that places a high demand on parental involvement (i.e., attending weekly therapy sessions during work hours and policies that require parents to be present). In addition, even if services are covered, many children are authorized for a fixed number of sessions, and parents often are not able to afford sessions beyond what is covered. Even when covered, out-of-pocket costs for families can exceed what many are able to afford. As such, it is critical that families receive quality therapy in the limited number of sessions available to them in order to get the most out of the services they are able to receive.

Finally, while these types of services may be needed for children with many types of special needs, often coverage is only included for those with a particular diagnosis (e.g., ASD). A plan could be developed to assist families that do not qualify for services under public or private insurance to be able to receive therapy of services either pro-bono, or at a lower cost through grants.

In our current sample, many differences were found with respect to perceived difficulty of access to services based on race and ethnicity. Caregivers of White children agreed more that it was difficult to access specialized services, caregivers of Hispanic children agreed more that it was difficult to access mental health services, while caregivers of Black children reported less difficulty accessing services. It is important to note that these results do not necessarily reflect a disparity in services, but represent the perceptions of parents. One possibility is that the perceptions of caregivers belonging to various racial and ethnic groups may be linked to different expectations regarding services (i.e., ease access to and quality of services).

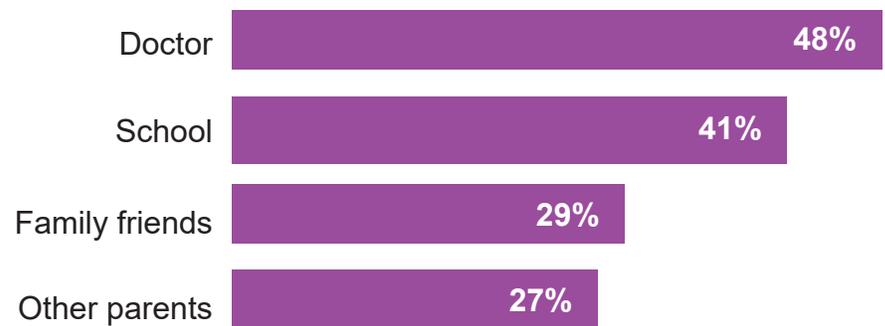
A quarter of caregivers reported having to reduce work hours, 18% left their jobs and, 16% reported not being able to leave their job because of insurance concerns. It is important to consider that families with more financial resources at their disposal have a greater ability to allow a caregiver to reduce work hours or to leave a job altogether. This may not be an option for families that require two incomes to make ends meet or for single parent households.

3. Community Based Services and Supports

CYSNS Survey Findings: Caregiver Perceptions

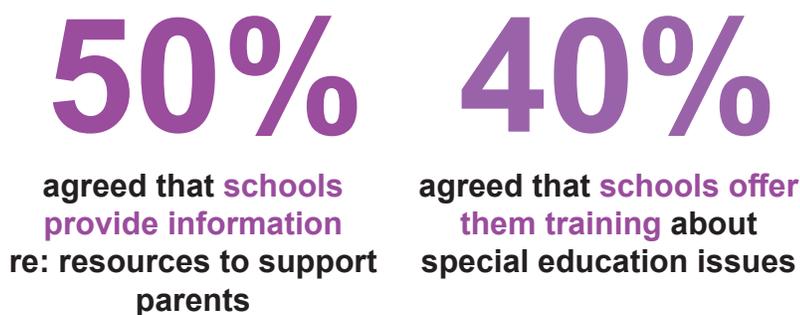
Caregivers were asked to respond to a series of questions related to the supports they have received from service providers throughout the community. First, caregivers were asked where they go for information about where and how to obtain help for their child’s special needs or behavioral health concerns. Most parents reported going to their child’s doctor (48%) or their school (41%). Additionally, many parents often look to family friends (29%) or other parents (27%) for this information.

Figure 18: Caregiver Responses to CYSNS Questions: Sources of Information on Available Services



SOURCE: CYSNS Survey, Q-Q Research, 2018

Figure 19: Caregiver Responses to CYSNS Questions: Information Available from Schools



SOURCE: CYSNS Survey, Q-Q Research, 2018

About half of caregivers agreed that their child’s school provides information about organizations that offer support for parents of students with disabilities. Approximately 40% of caregivers agreed that their child’s school offers them training about relevant special education issues. No differences were found with regard to the questions by child sex, race or ethnicity.

Focus Group Findings

Caregiver Perceptions

Parents were asked what types of resources they needed from the community to meet their child’s needs. The most common types of resources parents say they required were accurate sources of information and services available for their children, along with support systems for themselves. Across all four parent focus groups, parents were able to identify a long list of resources they have relied on in Broward County, and parents responded by listing the following resources:

| | | | |
|-----------------------------------------------------------------------|--------------------------------------------------------------|--------------------------------------------------------------------|-----------------------------|
| Early Steps | Florida Diagnostic & Learning Resource System (FDLRS) | Cleft and Craniofacial Center at Joe DiMaggio Children’s Hospitals | Autism Committee (ACE) |
| Autism Speaks | Healing Arts Institute | South Florida Wellness Network | ESE Advisory Council |
| 2-1-1 Broward | Child Find | Denise’s List | Chrysalis Center |
| University of Miami Center for Autism and Related Disabilities (CARD) | University of Miami Autism Spectrum Assessment Clinic (ASAC) | Parental Information Resource Center in Broward (PIRC) | Henderson Behavioral Health |

In addition, parent focus group participants were asked to name community-based recreational resources available in Broward County for children with special needs. The participating parents listed many organizations that provide sports and enrichment activities, including: Weston soccer clubs, Miracle League Baseball, JCC Jamboree, Nova, I-9 Sports, YMCA, Cooper City Cyclones Swim Club, American Youth Soccer Organization (AYSO), Spectrum Dance, and Circle of Friends.

Support groups, whether in the community or at the child’s school, were critical sources of information and emotional support for parents. One mother shared her experience at her child’s school:

“The autism coach created a support group because she saw the need... Twice a year we have a parent resource day, where we tell her what kinds of issues we’re struggling with, and she brings in experts to talk to us.”

When asked how resources for parents could be improved, or what resources could be added, their responses included culturally appropriate supports, educational guidance, care coordination and family therapy.

“God help you if you’re a parent that doesn’t speak English. Even though we have the 10 translators there, there’s still: now where do you go?”

“You should not leave an IEP meeting lost or wondering what’s going on.”

Expert Opinions

Experts also weighed in on community resources that were needed or could be improved. Extended-hour programs are a critical need for working parents, as well as community-based programming delivered close to where families live. Parents of youth and young adults with disabilities would like to see more summer jobs available.

Providers agreed that more recreational summer and out-of-school time programs are needed in Broward County, regardless of whether they focus on children with special needs or not. Broward County Parks and Recreation does not offer summer programs for children with special needs only.

Another important gap identified by recreation providers are programs capable of working with children and youth with emotional or behavioral issues. Recreational programs for children with special needs are not available in the north of Broward County.

The main recommendation from expert participants was to expand partnerships between service agencies and municipal providers.

Key Points and Recommendations

Pediatricians, family and friends, and other parents were reported by caregivers as important sources of information and support. This finding further strengthens the previous recommendation about the need to educate not only health care providers, but also the community at large, regarding signs of special needs, and the supports and resources available.

Support groups, whether in the community or at the child's school were cited as critical sources of information and emotional support for parents and were highly valued. One recommendation would be to increase and promote support groups for caregivers of children with special needs. According to the data, parents value the opportunity to interact with other parents and see them as important sources of information. Equipping pediatricians with information to enable them to refer parents to support groups and services is another avenue to connect parents and caregivers to this supportive resource.

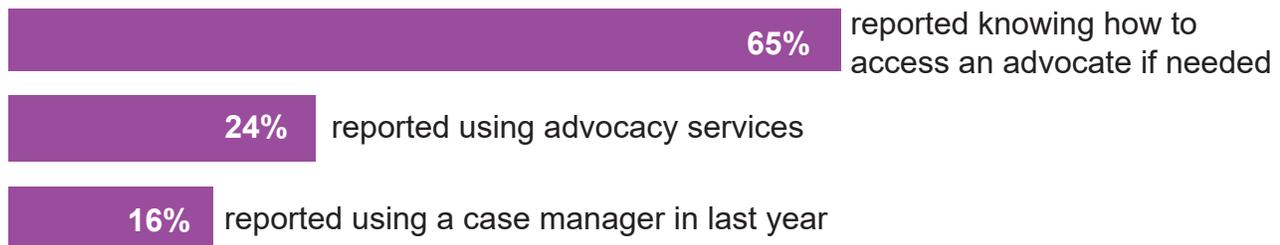
Caregivers also reported reaching out to their child's school to receive important information, but almost half of the sample reported not receiving enough information about their child's special needs from their school. A partnership with the school system to offer more support and educational resources through the school sites may be better to reach parents and help address their need for support. Perhaps implementation of parent workshops and training for youth with special needs can be set up using a systematic approach, as is done in the Los Angeles Unified School District (LAUSD), if it is not being done already. The LAUSD requires mandatory items in each child's IEP that include parent workshops and training.

4. Care Coordination/Family Service Provider Partnerships

CYSNS Survey Findings: Caregiver Perceptions

Caregivers were asked to respond to a series of questions related to the coordination of care among the various providers that work with their child with special needs. Only 16% of caregivers reported using a case manager in the last year, and 24% reported using advocacy services for assistance.

Figure 20: Caregiver Responses to CYSNS Questions: Care Coordination and Advocacy

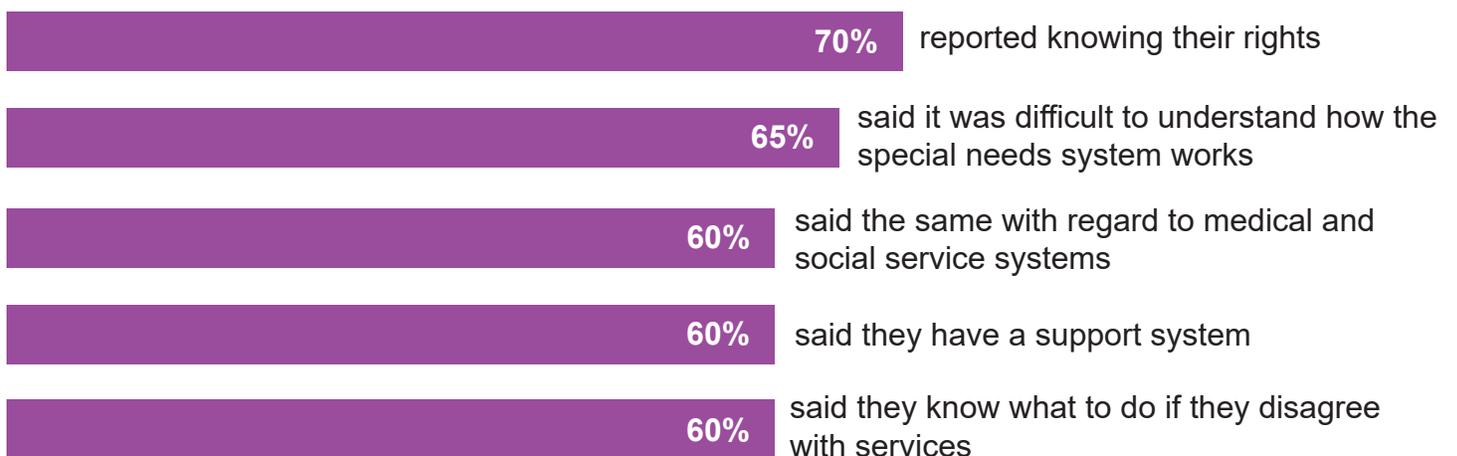


SOURCE: CYSNS Survey, Q-Q Research, 2018

More than half of caregivers (54%) reported that they usually or always received the help that they needed coordinating their child's care, 31% reported getting help sometimes, and 15% responded that they never receive enough assistance. Parents were split when asked if they received enough help coordinating care (half positive, half negative). Differences in responses to the survey items discussed above were explored by sex of child, race and ethnicity variables. When asked about using a case manager, caregivers of Black children were significantly more likely to report using a case manager to help coordinate services than caregivers of non-Black children. In addition, caregivers of White children were significantly less likely to report using a case manager to help coordinate services than caregivers of non-White children. Moreover, caregivers of White children were significantly less likely to report getting as much help as they needed; caregivers of Black children were significantly more likely to report getting as much help as they needed.

Approximately 70% of caregivers reported knowing their rights to services, and 60% of parents say they know what to do if they disagree with services. At the same time, 65% of caregivers reported that it was difficult to understand how the special needs system worked, and 60% said the same with regard to medical and social service systems. Almost two-thirds (65%) of caregivers reported knowing how to access an advocate if needed. Finally, about 60% of parents reported having a support system.

Figure 21: Caregiver Responses to CYSNS Questions: Caregiver Advocacy Knowledge



SOURCE: CYSNS Survey, Q-Q Research, 2018

Focus Group Findings

Caregiver Perceptions

Parents acknowledged that in order for care coordination to be effective, they must play a big role in bridging information gaps among the many providers working with their children in and out of school.

“I call myself “momvocate.” I felt like there was a system, or there was a service that was missing between point of diagnosis, schooling, therapeutic services, et cetera, et cetera.”

To be as effective as possible, many parents reported having taken trainings to learn their children’s rights. However, as the child’s needs change over time, so does the information needed, and staying on top of all this is challenging for caregivers.

In addition, professional advocates are highly valued by parents who have access to them. Not only do advocates provide parents with information about their rights and help set the right expectations, they are also a source of emotional support and guidance.



Expert Opinions

One primary issue discussed as it related to care coordination is caregiver awareness and knowledge of the system of care. According to experts, despite their best efforts to educate parents, parents' lack of knowledge regarding services available interferes with service delivery.

"We're having a real struggle with the parents at this point with the rights and knowing where to go and what to do, and about the IEPs that they sign."

All agreed that advocacy supports are crucial, particularly as it pertains to the education system. Beyond immediate needs, parents also need help planning for the long-term needs of their children early enough, so assistance is there when they need it. Participants also agreed that improved community awareness of disabilities in general is needed, along with suicide intervention and prevention training.

Another issue facing the system of care is capacity. While the current system of care is effective in some cases, capacity is stretched by high demand. According to one participant, there are 34,000 children in Broward County with an IEP or a 504 plan, and the Early Learning Coalition has a long waiting list.

There was consensus among participants that public school general education teachers need additional training and resources to effectively support children with special needs.

"Our teachers, I think, truly deserve some more support and more ongoing training. I think that they're very much taxed with (how) to implement the IEPs."

In their opinion, universities are not preparing teachers to work with special needs students, and once teachers start working, training capacity is stretched thin by high demands. The group mentioned the upcoming BCPS mandatory mental health training provision as a step in the right direction in terms of teacher capacity building.

According to service providers, collaboration with the school system has its own challenges, among them, variations in leadership and school culture may contribute to incongruity in perspectives or approaches regarding the best way to serve children with special needs. Another challenge experts presented was high turn-over and caseloads among ESE specialists resulting in loss of critical referral information and minimum individualization of services. General education teachers are also burdened by collaboration demands.

According to participants, another general obstacle to collaboration is the provider community's lack of knowledge of what is available and by whom. Privacy restrictions may also present barriers to accessing client information needed to coordinate / provide services in a timely manner, and therefore may preclude or delay collaboration efforts as well. Providers also agreed that collaboration is time consuming for agencies stretched thin. Some felt that mandatory collaboration requirements by funders may be the only way to enforce this.

5. Transition Support

CYSNS Survey Findings: Caregiver Perceptions

Caregivers were asked if their child with special needs had transitioned out of services, and 66 caregivers indicated their child had indeed transitioned. Data presented in this section includes responses of parents who responded “yes” to their child transitioning out of services. The responses to questions regarding transitions were mixed. Only half of caregivers agreed that school provided information on agencies that can help with transition. Half of the sample agreed that they received support through the transition, half did not. When asked if they were satisfied with their transition experience, 60% reported being satisfied.

With respect to transition to adulthood, only 20% reported receiving financial education and employment support, less than 25% reported using vocational rehabilitation services, and less than 30% responded that they were referred to post-secondary options.

Focus Group Findings

Expert Opinions

With respect to transition support, expert participants identified two challenges impacting youth and young adults: 1) service interruption when youth enter the juvenile justice system, and 2) overprotective parents of transitioning youth.

“Some of the experience that we have with some of our cultures and our independence teams is that a parent might not let us teach a youth to ride the bus or how to apply for a position just because they have that fear they’re going to fail.”

Participants also agreed that mental health services for young adults past the age of 21 are basically not available. As someone stated,

“A lot of mental health services for children. Don’t get to 21, because there will be none.”

Many of these underserved young adults end up in the justice system. One area where participants felt additional collaboration was needed was around transition services for young adults, particularly connecting youth with the workforce board.

Experts also remarked that, for low income parents, their child’s Supplemental Security Income (SSI) checks have become part of the household’s income. In many cases, fear of losing those benefits drives them to keep their adult children with special needs from entering the job market, even if they are capable of working.

Key Points and Recommendations

Transition support needs to be improved at all levels. Regarding to transition to adulthood, the majority of parents reported they did not receive the services that are currently available. It is unclear if this represents a problem of capacity, an awareness issue, or both.

Help is needed to prepare parents and children for transitions to adulthood. This includes, but is not limited to financial and guardianship planning, employment, and independence planning.

Encouraging parents to stay actively involved in the IEP process throughout middle and high-school may be beneficial. Parents that stay involved throughout their student's educational career may fare better in linking their children to transitional services. Often as children get older, students attend their meetings alone, leaving children to advocate for their needs on their own.

Starting the transition support process earlier (i.e., 14 or 15 years of age) may help parents that are hesitant to engage in the process. In addition, to bridge the transition gap (i.e., gap between the time students leave high school and access transition services) systems of care can consider coordinating with transition partners to visit schools and work with students starting in 11th grade. This could be achieved during or after school through work readiness classes and/or summer internship opportunities. These could be made possible by government grants to the agency.

As many experts have relayed that schools are under resourced, perhaps the creation of a Transition Coordinator position that can be shared between high schools could assist with transition planning. The Transition Coordinator could plan on-site school visits for a first-hand view of transition opportunities and assist transitioning youth with interviews and vocational planning. This position would help facilitate access to federal and state transitional services through agencies.

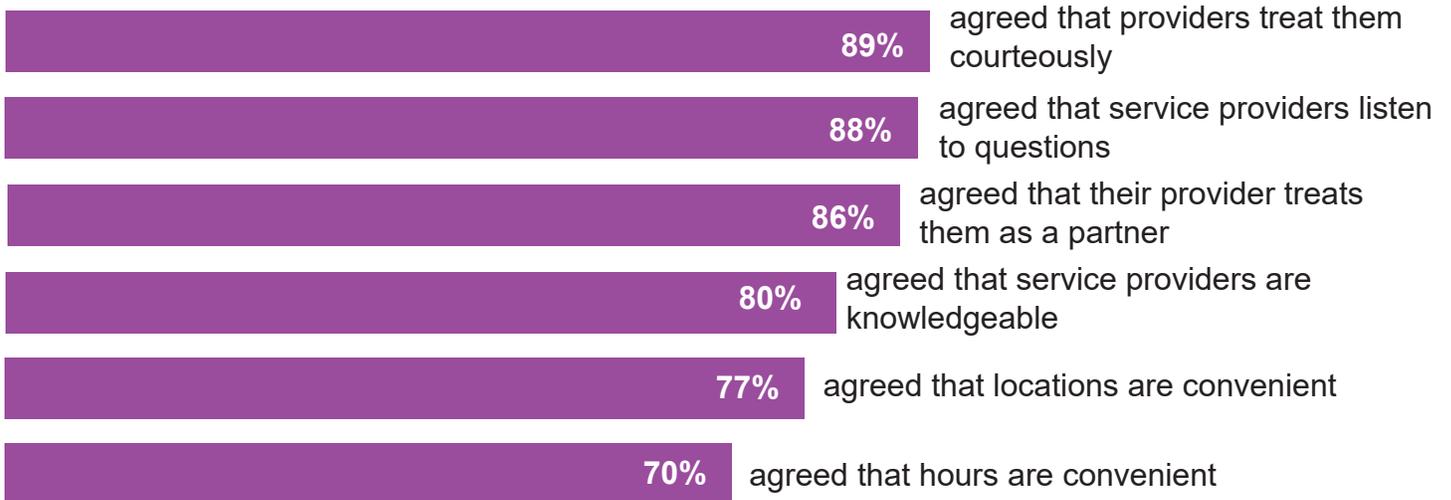


6. Customer Experience

CYSNS Survey Findings: Caregiver Perceptions

Caregivers were asked to respond to questions regarding the quality of service and their satisfaction with interactions with service providers. Responses from caregivers were positive overall. For the most part, caregivers agreed that service providers were knowledgeable and listened to their questions about their child with special needs. Caregivers mostly agreed that service providers' locations and hours were convenient. When asked if they felt that providers treat them courteously and as partners in their child's care, caregivers agreed that providers do well in these areas. There were no differences in the responses of caregivers by sex of child, race, or ethnicity.

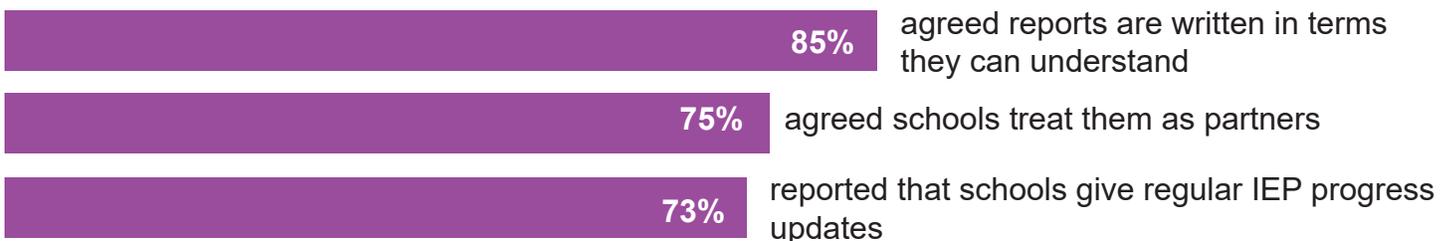
Figure 22: Caregiver Responses to CYSNS Questions: Caregiver Advocacy Knowledge



SOURCE: CYSNS Survey, Q-Q Research, 2018

Caregivers were asked to respond to questions regarding the quality of services and their satisfaction with interactions with services provided by the schools. Responses to these questions were also positive. About 75% of caregivers agree schools treat them as partners, and 73% agreed that schools provide them with regular IEP progress updates about their child. Moreover, 85% of caregivers agree that IEP reports are written in terms they can understand. Caregivers of Black children with special needs were significantly more likely to agree that their school treated them as partners than caregivers of non-Black children. No other differences were found by gender and ethnicity.

Figure 23: Caregiver responses to CYSNS Questions: Caregiver Advocacy Knowledge



SOURCE: CYSNS Survey, Q-Q Research, 2018

Focus Group Findings

Caregiver Perceptions

Parent focus group participants were asked about the quality of and satisfaction with services they have received both from service providers within and outside the school system. A majority of comments regarding factors determining service satisfaction pertained to education and services provided by the school system. Parents spoke about a positive school environment being key to parental satisfaction. Specific factors included: principals and general education teachers trained in special education, low teacher turnover and high consistency, school-specific providers, integration/inclusion in general education classes, behavioral supports in school, ESE certified teacher at each grade level, admission of out-of-state diagnostic and assessment results, and respect for parents' wish of removing, or changing their child's placement.

In terms of education, a major challenge parents identified is high staff-to-student ratio for special need services.

"Schools have 10 kids in speech therapy. It's not individualized, even though they call it an IEP, it's not."

Along the same lines, parents felt general education classes are too large and teachers are overburdened and under-trained to deal with children with special needs, particularly those with emotional or behavioral problems. High teacher turn-over is another challenge to educational continuity for these families.

"My son is 14-years-old, he has the speech of a 5-year-old, and it took them an entire year to provide him with assistive technology."

Outside of school, parents' satisfaction was tied to: 1) consistent assessment requirements, 2) effective care coordination, 3) trust and consistency of providers, 4) regular progress monitoring, 5) service continuity despite lack of progress, and 6) insurance coverage for basic services.

Key Points and Recommendations

Overall, parents are highly satisfied with community service provider quality and treatment. Barriers exist for 20 to 30% of families with regard to hours and locations. No ethnic or racial disparities with respect to service satisfaction were identified.

Most parents reported being satisfied with their IEPs, communication from the school regarding progress, and understand what they are being told by school personnel. But, only half of parents reported that school provided them with information about additional support, and most report that the schools do not offer them additional training, as previously discussed. So, while parents aren't receiving as much information from the school as they would like, they are for the most part satisfied with the services they do receive.

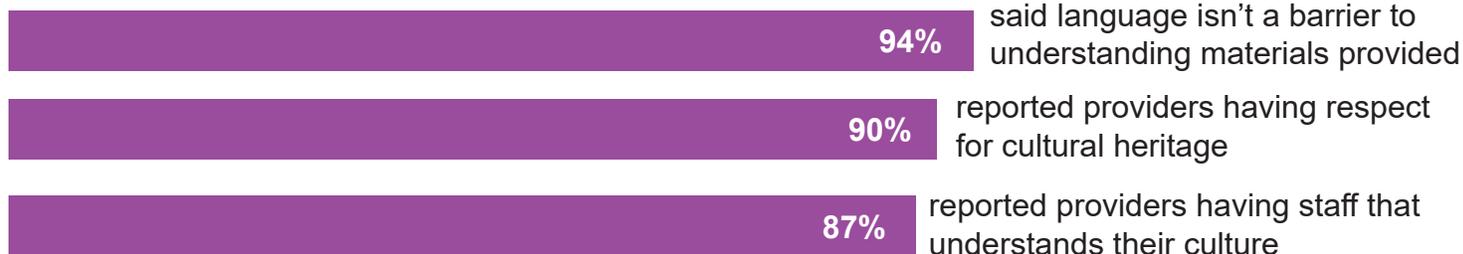
According to caregiver perceptions, more training for general education teachers is needed. Schools of higher education should consider requiring classes on ESE education for all majors and offering ESE certifications and refresher courses to professionals.

7. Service Disparities

CYSNS Survey Findings: Caregiver Perceptions

Caregivers were asked to respond to questions regarding any challenges they may have faced in dealing with the service system that they perceived to have been related to their race or ethnicity. About 90% of caregivers reported service providers having respect for their cultural heritage. Likewise, 87% of caregivers reported that providers are staffed with individuals who understand their culture. When asked about language being a barrier to receiving or understanding material provided, 94% of parents said language is not barrier in their understanding. Also, 10% agreed that a service provider or a teacher attributed their child's disability to another language being spoken.

Figure 24: Caregiver responses to CYSNS Questions: Cultural Responsivity of Providers



SOURCE: CYSNS Survey, Q-Q Research, 2018

Around 10% of the caregiver sample agreed they have faced discrimination when seeking services. Similarly, 12% agreed a service provider or teacher treated their child differently due to their race or ethnicity. When examining these questions by child race and ethnicity, the caregivers of Black children were significantly more likely to agree that they faced discrimination or were treated differently than the caregivers of non-Black children. It is important to note, however, the caregivers of Black children generally disagreed that they faced discrimination. In other words, their average responses when asked if they faced discrimination indicated disagreement with the statement.

Figure 25: Caregiver responses to CYSNS Questions: Caregiver Experiences with Discrimination



SOURCE: CYSNS Survey, Q-Q Research, 2018

Focus Group Findings

Caregiver Perceptions

Caregivers that participated in focus groups acknowledged many challenges they have faced related to income, race and ethnicity, cultural norms, language, immigration status, income, marital status, and geographical location. The comments below illustrate the concerns:

“Because we’re working parents and we’re middle income, we made too much money to receive help but not enough money to afford what our kids need.”

(My children are half Black. I) “got through the phone conversation, everything was great, I walked in, they met me, met my children and next thing I know it’s ‘Well, you’re a single mom?’ And then (they) find out that I’m Caucasian, all of a sudden they want to talk to me differently.”

“I’m from India, and it’s a taboo to call for help, or mental health in our family, or in our culture. It’s a big deal. I had to do it. I wanted to help my son. I feel that the counselors should get prior knowledge what they’re dealing with.”

Expert Opinions

Expert focus group participants also recognized several challenges related to socio-demographic factors, including lack of affordable insurance and high deductible costs, immigration status, and language. Cultural competence goes beyond providing translation services, and participants felt providers are falling short in this area. Even when providers understand the need to have culturally competent staff, hiring from different racial or ethnic communities is challenging.

“I don’t think we have enough providers that really look at cultural aspects of the family. I think we just mesh everybody within ... sort of like, the providers, and say, ‘Oh yeah, I have one or two staff that speaks Spanish and one or two staff that speak Creole,’ and that is supposed to be culturally competent, and it isn’t.”

Experts also report that immigrant status challenges have become more prominent recently. Even if minors are born in this country, they cannot be served unless their parents are documented. For those without documents, fear of deportation keeps them from seeking social security or Medicaid benefits for their children.

“People who are residents are now afraid to get free medical care, because they’re afraid that would not allow them to become citizens when they’re eligible.”

Key Points and Recommendations

Overall caregivers were mostly satisfied with the cultural responsiveness of service providers. That being said, 1 in 10 families did agree with statements indicating that they have faced discrimination based on race, ethnicity, or the language they spoke. Caregivers of Black children were more likely to agree that they faced discrimination. This suggests that more training is needed for providers with regard to racial or ethnic discrimination.

■ Conclusion

Foundational issues for families with children with special needs are considered to be needs and opportunities that affect the lives of youth at many levels and across multiple areas. These issues must be addressed to improve the lives of these children in Broward County. Data leading to the identification of foundational issues have been presented throughout this report. Many of the concerns and needs raised by families have their basis in several central issues including:

- 1) Difficulties in accessing care due to caregivers' lack of knowledge about what their child needs and how to navigate the system of care,
- 2) Difficulties in receiving quality care due to problems of capacity with roots in lack of funding and resources, and
- 3) Difficulties in receiving care based on cost and eligibility.

In general, caregivers feel that providers have been supportive and culturally responsive, though data do indicate that providers could benefit from additional training as some caregivers did report facing discrimination. Several community assets were identified by caregivers and experts that can be leveraged to improve services. Through this Special Needs System of Care Assessment, stakeholders now have a comprehensive set of data, analyses, and findings that they can use to develop priorities, recommendations, and strategies to address the identified needs and gaps and opportunities to develop approaches for advocating for policy and procedure changes. Stakeholders can also use this data to continue to improve utilization and mobilizing of existing community resources.

■ References

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