

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

APPENDIX



APPENDIX A

Assessment Methodology

In order to meet the key objectives of this Special Needs System of Care Assessment (SN SOCA) project, 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 the sections that follow.

Community-Based Participatory Approach

Q-Q Research utilized a community-based participatory approach for the SN SOCA. This approach 1) allowed for feedback and input regarding the assessment plan; 2) empowered stakeholders to voice their experience around serving the special needs population; and 3) ensured that the research team was in alignment with the vision and purpose of the assessment.

Q-Q Research began the assessment with a meeting with CSC staff and the SNAC committee to gather documents and any relevant reports for review. During this meeting, the research team gathered background information, including the activities or discussions that led to the decision to conduct the assessment. CSC staff provided a list of organizations and key stakeholders.

Next, the research team facilitated visioning sessions with the SNAC and all councils that are a part of SNAC (e.g., Baby SNAC, Primary SNAC, Tween SNAC, Transition SNAC, Special Needs/Mental Health Bridge, etc.). The purpose was to gain a clearer understanding of stakeholders' desired basic requirements for the needs assessment process in order to guide the research team in developing key questions.

Background and Problem Significance

Understanding the scope and nature of special needs among children is crucial for the understanding of the problems and dilemmas faced by children with special needs and their families. This information is vital not only for the examination of the provision of current services, but also for the preparation needed to meet the community's prospective needs. As such, a variety of relevant national, state, and county level data are provided in the section that follows to create context for the extent of the issues faced by children and families.

Global and National Data

A major issue that policy makers and providers face when planning for the concurrent and prospective needs of families with special needs children is inherently related to the problems in estimating the number of children with special needs.¹ Exploring the issue on a global scale, approximations of the prevalence of children with disabilities vary markedly subject to the classifications and definitions used to define disability. The United

Nations Children's Fund (UNICEF) projected approximately 150 million children worldwide under the age of 18 are affected by disabilities, though the number could be much higher.²

In the United States, over 3 million or approximately 6.2% of children are classified with a disability.³ Congress reauthorized the *Individuals with Disabilities Education Act* (IDEA) in 2004 which makes available public education throughout the nation to ensure that children and youth with special needs receive not only education but other essential related services. IDEA was recently amended through the "Every Student Succeeds Act", in December 2015.⁴ The law states "Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society. Improving educational results for children with disabilities is an essential element of our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities."⁵ IDEA defines a "child with a disability" as any child with:

"mental retardation, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities; and who, by reason thereof, needs special education and related services".⁶

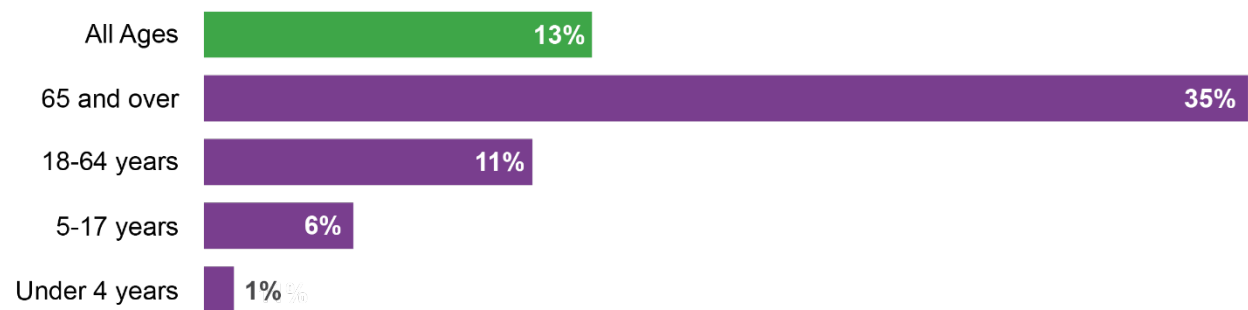
The IDEA directs states and other public organizations to provide a variety of services to children with special needs including early intervention and special education and related services to more than 6.5 million children and youth with special needs.⁷ For children that have been identified and meet the criteria to qualify for services under IDEA ages 3 and above, an Individualized Education Plan (IEP) is required to guide the provision of services. For young children with developmental delays under the age of 3, an Individualized Family Service Plan (IFSP) is provided. While a standardized definition such as the one presented by IDEA is helpful for the establishment of prevalence data, IDEA estimates only comprise children and youth who were screened for a disability and met criteria. Many disabilities may go unidentified for long periods of time, while others may be sufficiently impairing but do not fit under the aforementioned definition. The federal government sets policies under IDEA, and then state and local authorities share the authority over funding, rules and curricula as related to provision of education and other services.

Several categories of disabilities, including developmental delays and behavioral concerns are not identified as early as they could be. Without identification, children are not able to receive the services and assistance they need to do well with family, at school, and with friends. In the United States, the CDC estimates about 1 in 6 children aged 3 to 17 years have one or more developmental or behavioral disabilities, such as autism, a learning disorder, or attention-deficit/hyperactivity disorder.⁸ Furthermore, many children have deficits in other areas that can affect their daily lives. Unfortunately, many children with disabilities are not identified until they enter school. By this time, some significant

delays are likely to have occurred and the critical windows for treatment might have passed.⁹

The American Community Survey (ACS) administered by the U.S. Census Bureau assesses basic data regarding the special needs population that assists in describing the communities of children with Special Needs in the United States. The definition of disability used by ACS is similar to IDEA’s definition, though it may or may not capture children who have been screened and qualify for services under IDEA. ACS defines a person with a disability as a person having “vision, hearing, cognitive, ambulatory, self-care, or independent living difficulty”.¹⁰ According to the 2017 Disability Statistics Annual report which uses data captured in 2016 by the ACS, the prevalence of disability in the United States was approximately 0.4% for children under 4 and 5.6% percent for children and youth between the ages of 5 and 17.¹¹ Approximately, 21% of individuals with a disability live in poverty.¹²

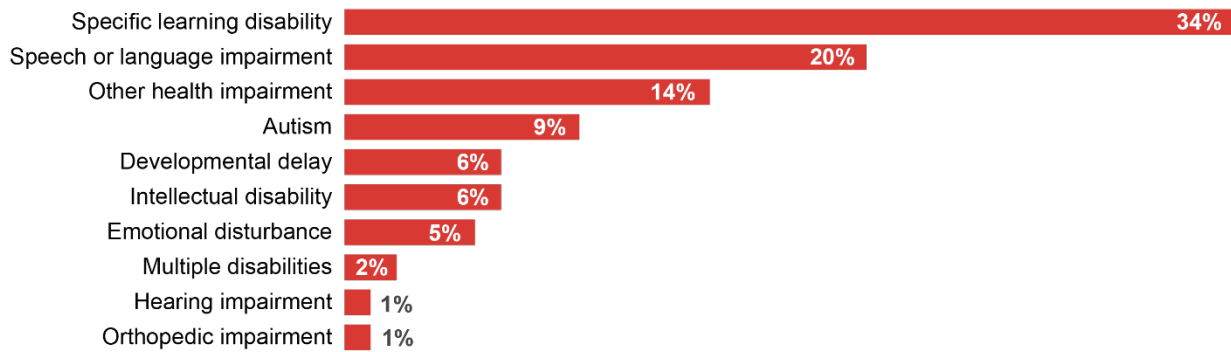
Figure 1. Prevalence of Disability in the U.S. by Age



SOURCE: U.S. Census Data, American Community Survey, 5-year estimates, 2012-2017

The majority of school aged children living in Metropolitan areas in the US are provided education through public education agencies (approximately 89%).¹³ In 2015–16, approximately 6.7 million students aged 3–21 were classified as Exceptional Student Education (ESE) students receiving special education services which represents about 13% of all public-school students.¹⁴ Nationally, about 34% percent of ESE students were classified as having specific learning disabilities, 20% had speech or language impairments, 14% were classified as having other health impairments (having limitations related to chronic or acute health problems), and 9% had Autism. Additionally, students with intellectual disabilities, developmental delays, and emotional disturbances each accounted for between 5 and 6 percent of the national student ESE population. Students with other disabilities such as hearing impairments, orthopedic impairments, visual impairments, traumatic brain injuries, deaf-blindness, and students with multiple disabilities each represented less than 2% of the national ESE population.¹⁵

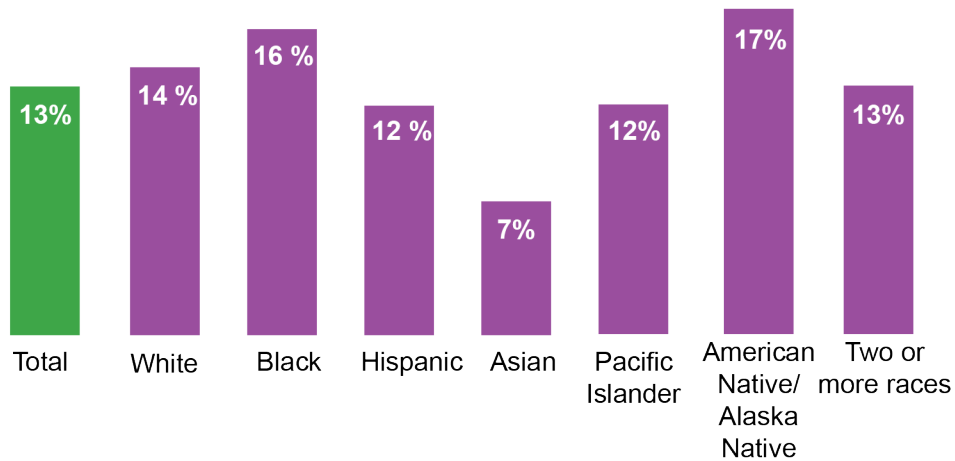
Figure 2. Percentage of ESE students aged 3-21 served under IDEA in the US: 2015-16



SOURCE: U.S. Department of Education, Office of Special Education Programs, Individuals with Disabilities Education Act (IDEA) database, retrieved from <https://www2.ed.gov/programs/osepidea/618-data/state-level-data-files/index.html#bcc>.

In 2015-16, more males (17%) than females (9%) between the ages of 6 to 21 were classified as ESE in the U.S. The percentage of students classified as ESE served under IDEA between the ages of 3 and 21 also differed across race/ethnicity. Among the various races/ethnicities, the highest percentages of students classified as ESE were for those who were American Indian/Alaska Native, followed by students who were Black, White, of Two or more races, Hispanic and Pacific Islander, and Asian.¹⁶

Figure 3. Percentage of ESE students aged 3-21 served under IDEA by Race/Ethnicity in the US: 2015-16



SOURCE: U.S. Department of Education, Office of Special Education Programs, Individuals with Disabilities Education Act (IDEA) database, retrieved from <https://www2.ed.gov/programs/osepidea/618-data/state-level-data-files/index.html#bcc>

While special education programs provide essential services and supports for children with special needs, research has shown that minority students face many challenges that impact their ability to be successful. According to National Assessment of Educational Progress (NAEP) data, in 2015, less than 5 percent of Black and Hispanic 12th-grade students with disabilities scored as proficient in reading and math.¹⁷

For the most part, minority students are overrepresented among children with disabilities with Black and Native American students being far more likely to be identified as having disabilities than other subgroups.¹⁸ The overrepresentation of these groups varies across disabilities is more likely to occur for some of the most commonly diagnosed disabilities. For example, Black youth are two times as likely to be classified with an emotional disturbance or an intellectual disability as their counterparts of other races, while American Indian youth are two times as likely to be classified with specific learning disabilities, and four times as likely to be identified as having developmental delays.¹⁹

State of Florida and Broward County Data

It is estimated that as of 2017, there were over 4,000,000 children under 18 living in the State of Florida, with approximately 4.3% having a disability.²⁰ Almost 390,000 children between the ages of 3 to 21 received services in Florida under IDEA in 2017-18 (see Table 1). Among children ages 3 to 5, the most common disabilities were developmental delays (53% of children with a disability ages 3 to 5) and by Speech or Language Impairments (32% of children with a disability ages 3 to 5). Among youth ages 6 to 21, the most common disabilities were specific learning disabilities (42% of youth with a disability aged 6 to 21), Speech or Language Impairments (23% of youth with a disability aged 6 to 21), followed by other health impairments (11% of youth with a disability ages 6 to 21) and Autism (10% of youth with a disability aged 6 to 21).²¹

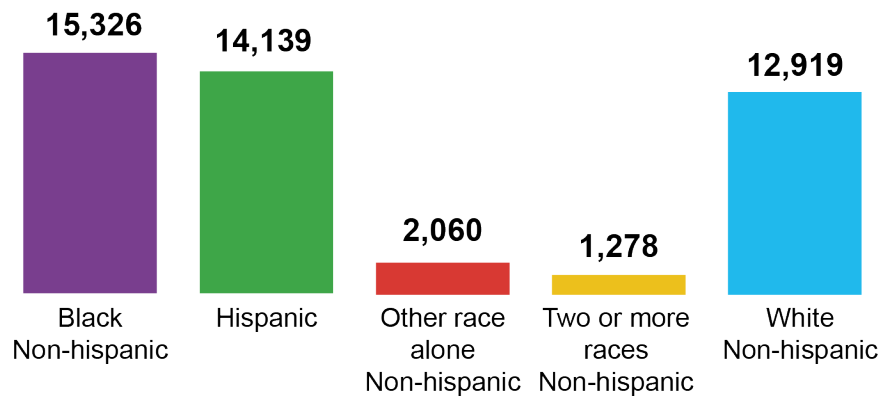
Table 1. Florida Students receiving Services under IDEA by Disability Type: Part B Child Count and Educational Environments

Disability Type	3 to 5 years	6 to 21 years
Autism	3,737	36,474
Deaf-blindness	13	84
Developmental delay ³	21,100	-
Emotional disturbance	63	14,933
Hearing impairments	427	3,898
Intellectual disabilities	528	24,710
Multiple disabilities	-	-
Orthopedic impairments	208	2,469
Other health impairments	696	39,833
Specific learning disabilities	81	145,893
Speech or language impairments	12,874	79,723
Traumatic brain injury	26	504
Visual impairments	109	1,243
All disabilities	39,862	349,764

According to Florida Kid Count, in 2017, there were 397,910 children and youth under 18 living in Broward County, representing 21.2% of the County's total population. It is estimated that about 18% of these children (73,178) live in poverty. The poverty threshold used in this calculation is an income of less than \$24,858 for a family of two adults and two children in 2017.²²

These data indicate that approximately 45,722 children in Broward County can be classified as having special needs and are enrolled in ESE programs in both public and private schools.²³ With regard to race and ethnicity, the largest percentage of students classified as ESE in Broward County identify as Black Non-Hispanic (33.5%), followed by Hispanic (30.9%), and then White Non-Hispanic (28.3%) (see Figure 5).²⁴

Figure 4: Students enrolled in ESE programs by Race and Hispanic Origin in Broward County

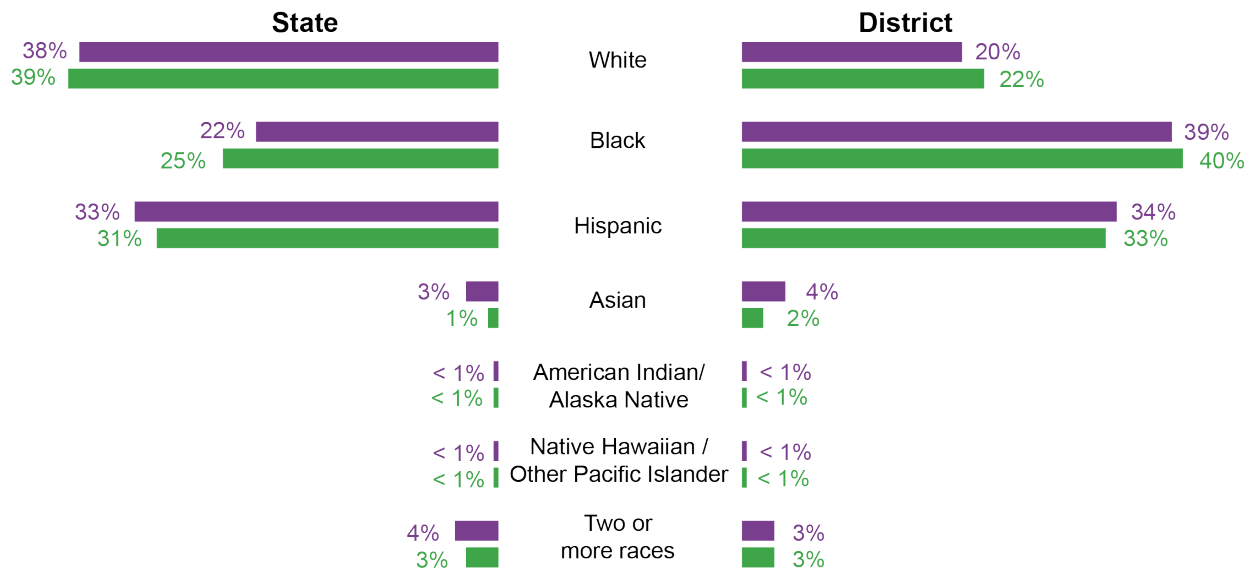


Source: KIDS COUNT Data Center, datacenter.kidscount.org (a project of the Annie E. Casey Foundation)

In 2018-19, according to Broward County Public Schools (BCPS) website, 36,176 youth with special needs were served under IDEA, representing 13.4% of BCPS students. Among youth classified as ESE, approximately 11,000 (32%) have been identified with Specific Learning Disabilities, approximately 4,800 (14%) with Autism, and another 2,000 (5%) with intellectual disabilities. A continuum of services and programs are available to meet the individual needs of students eligible for special education and related services, ages 3 through 22 through BCPS.²⁵

As reported in October of 2017 by the Florida Department of Education Bureau of Exceptional Education and Student Services in their 2018 LEA Profile of Broward County, the racial/ethnic membership data for all students and students with disabilities enrolled in the state and BCPS are presented below (see Figure 5). In BCPS, higher percentages of black students are classified as ESE than in the state, while lower percentage of white students are classified as ESE than in the state.²⁶

Figure 5: Racial/ethnic Demographic Data for Students in Florida as compared to Broward County Public Schools: 2017



Source: Reprinted from the Florida Department of Education Bureau of Exceptional Education and Student Services in their 2018 LEA Profile, <http://www.fldoe.org/core/fileparse.php/7672/urlt/Broward18.pdf>

Racial/ethnic data for students enrolled in BCPS classified as having a primary disability of Specific Learning Disabled (SLD), Emotional or Behavioral Disabled (EBD), or Intellectually disabled (IND) are presented for the state and BCPS in Table 2. BCPS has higher percentages of Black students classified as SLD, EBD, and IND than the state.

Table 2: Racial/ethnic Demographic Data by Disability Type for Students in in Florida as compared to Broward County Public Schools: 2017

	SLD		EBD		IND	
	State	District	State	District	State	District
White	35%	20%	37%	26%	32%	14%
Black	27%	42%	38%	47%	36%	54%
Hispanic	34%	34%	20%	22%	27%	27%
Asian	< 1%	1%	< 1%	< 1%	2%	3%
American Indian / Alaska Native	< 1%	< 1%	< 1%	< 1%	< 1%	< 1%
Native Hawaiian/ Other Pacific Island	< 1%	< 1%	< 1%	< 1%	< 1%	< 1%
Two or more races	3%	2%	5%	4%	3%	2%

Source: Reprinted from the Florida Department of Education Bureau of Exceptional Education and Student Services in their 2018 LEA Profile, <http://www.fldoe.org/core/fileparse.php/7672/urlt/Broward18.pdf>

Additionally, the Florida Department of Education reports risk ratios or “the risk that students of a given race will be identified as a student with a disability or a student in selected disability categories when compared to students of all other races. A risk ratio of 1.0 indicates the students of a given race are equally likely as all other races combined to be identified as disabled”.²⁷ The state requires Districts to set aside IDEA funds for coordinated early intervening services if any risk ratios exceed 3.5. A blank cell indicates less than 30 students of a specific race or ethnicity with the given disability.²⁸ In general, the ratios at the county level were similar to those at the state level (see Table 3).

Table 3: Risk Ratios by race/ethnicity by Disability Type for Students in in Florida as compared to Broward County Public Schools: 2017

State	IND	EBD	ASD	SI-LI	OHI-HH	SLD	All Disabled
White	.77	.96	1.13	1.27	1.29	.88	1.02
Black	1.98	2.10	.79	1.06	1.02	1.34	1.18
Hispanic	.74	.52	1.03	.78	.84	1.04	.91
Asian	.65	.08	1.5	.62	.26	.27	.50
American Indian / Alaskan Native	1.15	1.13	.82	1.03	.95	1.13	1.04
Native Hawaiian/ Other Pacific Island			.62	.83	.54	.65	.69
Two or more races	.81	1.32	1.07	1.10	1.01	.87	.98

District	IND	EBD	ASD	SI-LI	OHI-HH	SLD	All Disabled
White	.61	1.38	1.25	1.12	1.64	.96	1.07
Black	1.86	1.36	.68	1.04	.91	1.20	1.04
Hispanic	.71	.58	1.18	.97	.85	1.00	.97
Asian	.82		1.04	.65	.24	.38	.59
American Indian / Alaskan Native				1.44		1.11	1.15
Native Hawaiian/ Other Pacific Island							.59
Two or more races	.81	1.36	1.29	1.06	1.16	.84	1.02

Source: Reprinted from the Florida Department of Education Bureau of Exceptional Education and Student Services in their 2018 LEA Profile, <http://www.fldoe.org/core/fileparse.php/7672/urlt/Broward18.pdf>

In Broward County, the CSC is an independent taxing authority established by the county’s voters in 2000 and reauthorized in 2014. According to their website, “the CSC’s mission is to provide leadership, advocacy and resources necessary to enhance the lives of the children of Broward County and empower them to become responsible, productive adults through collaborative planning and funding of a continuum of services.” In pursuit of this mission, the CSC funds close to a hundred programs that serve children and families, acts an advocate for policies that protect the interests of future generations of children, and provides leadership that brings the child-serving

providers together. The CSC works with various community partners to help address many issues including Advocacy and Employment Support for Youth and Families with Special Needs.²⁹ In addition, CSC contracts with 2-1-1 Broward to provide a specialized hotline service for families of children ages 0-22 with disabilities including vision impairments, hearing disabilities, developmental disabilities, speech /language Impairments, and traumatic brain injury in hopes to connect them with services needed and guide them through the system of care.³⁰

APPENDIX B

Caregiver Survey

Survey Development

The research team held several meetings in order to discuss the development of the survey's broader content domains. The team also worked to construct and refine specific survey items. The composition of our team members for this project was intentional; the team is comprised of members who bring diversity, cultural competence, and extensive experience as a team to the project. In an effort to bring in fresh perspectives in terms of strategies for the special needs population in Broward County, Q-Q Research brought on two consultants from metropolitan cities, namely, New York and California to help inform survey development, strategies and recommendations. The research team identified the following content domains for inclusion in the survey: special need identification, screening, assessment, and referral; access to care; community-based services and supports; care coordination; transition support; customer experience; and family-service provider partnerships.

With regard to the creation of specific survey items, specific questions were created using the information provided by stakeholders at the initial visioning session described above, while others were provided directly by CSC staff. Some items were developed by the research team members. Several questions in the survey were obtained from the National Survey of Children's Health conducted by the U.S. Department of Health and Human Services, a prominent national survey focused on gaining a better understanding of the health issues faced by children in the United States today.³¹ A few items were derived from a parent survey developed by Wayne State University's Center for Urban Studies to evaluate parent experiences with special education for the Michigan Department of Education.³² Other questions included were derived from the *The Caring for My Child Survey* developed by researchers interested in racial and ethnic disparities faced by the caregivers of children with special needs.³³ In this survey, the authors designed items in order to tap into the challenges faced by caregivers of children with special needs in obtaining diagnoses and securing services and supports.

Once the first draft of the survey was developed, the research team held a session with SNAC Committee Chairs that focused on gathering members' feedback regarding the survey. The following is a listing of all organizations/members present at the survey review session:

Name	Organization
Sonja Clay	Broward County Public Schools / ESLS Department
Ellie Schrot	Children’s Diagnostic Treatment Center
Alison Rodriguez	YMCA of South Florida
Robert Mayersohn	Parent Advocate
Melanie Magill	CareerSource Broward
Billie Morgan	2-1-1 Broward
Leona McAndrews	Broward County Children’s Services Administration
Tiffany Lawrence	Broward Behavioral Health Coalition
Marissa Aquino	Children’s Services Council of Broward County

Members were provided the draft survey prior to the session and during this session, the research team shared the questions with members for questions and feedback. After the session, the research team revised the survey based on the feedback received from the session. The final special needs assessment survey was submitted to CSC staff based on pertinent feedback received from the session.

Caregiver of Youth with Special Needs Survey (CYSNS)

This survey is being conducted in order to better understand the needs of primary caregivers of children with special needs in Broward County. "Special needs" is defined as developmental delays, physical disabilities, special health care needs, learning disabilities, or emotional/behavioral disorders. This survey should take about 20 minutes. Your responses are completely voluntary and will remain anonymous. No one will be able to link your responses to you.

The Children Services Council of Broward County, Broward Behavioral Health Coalition, and Broward County Human Services and United Way of Broward County are sponsoring this survey. Your participation in this survey is voluntary and you can stop filling out the survey at any time. If you have any questions regarding this survey, please contact Q-Q Research Consultants at (305) 999-7772. Thank you for your help!

If you have more than one child with special needs, please answer questions based on your experiences with the child with the most severe special needs.

PART 1: Questions about your child with special needs

1) Has your child been identified with a disability?

- a) Yes → GO TO 2
- b) No → SKIP TO 3

2) Please answer the questions below about your child’s special needs. (Please select all that apply)

Diagnosis	Has your child received the following diagnosis? (Y or N)	If yes, at what age did your child receive this diagnosis? (____years _____months)	What type of provider diagnosed your child with this condition? (Primary Care Provider, Specialist, School Psychologist/Counselor, Other Psychologist, Psychiatrist, Social Service Agency, Other (please specify))
Autism Spectrum Disorder			
Deaf or Hard-of-hearing			
Developmental Delayed Birth-5 years old only)			
Dual-sensory impairment (deaf & blind)			
Emotional or Behavioral Disabilities			
Intellectual Disabilities			
Language Impaired			
Orthopedic Impairment			
Other Health Impairment: ADHD			
Other Health Impairment: Anxiety/Depression			
Other Health Impairment: Epilepsy			
Traumatic Brain Injury			

Specific Learning Disabilities			
Speech Impaired			
Visually Impaired			

- 3) How old is your child? _____
- 4) What is the gender of your child?
- a) Male
 - b) Female
- 5) Is your child Hispanic/Latino?
- a) No, not of Hispanic, Latino, or Spanish origin
 - b) Yes
- 6) Please select your child's race (check all that apply).
- a) White/Caucasian
 - b) Black/African American
 - c) Native American
 - d) Asian/Pacific Islander
 - e) Other
- 7) What is your relationship to the child?
- a) Parent (Mother or Father)
 - b) Grandparent (Grandmother or Grandfather)
 - c) Sibling (Brother or Sister)
 - d) Other Relative (e.g., Aunt or Uncle)
 - e) Legal Guardian
 - f) Foster Parent
- 8) Is your child receiving social security benefits (SSI/SSDI)?
- a) No
 - b) Yes

PART 2: Questions about your child's health and special needs services

Please answer the following questions about your child's health, the services your child with special needs has received, and your experiences with the system of care.

Questions about your child's behavioral health

- 9) DURING THE PAST 12 MONTHS, did this child's doctors or other health care providers ask if you have concerns about this child's learning, development, or behavior?

- a) Yes
- b) No

10) At any time DURING THE PAST 12 MONTHS, did this child receive **behavioral treatment for ADD or ADHD**, such as training or an intervention that you or this child received to help with his or her behavior?

- a) Yes
- b) No

11) At any time DURING THE PAST 12 MONTHS, did this child receive **behavioral intervention for anxiety or depression**, such as training or an intervention that you or this child received to help with his or her thoughts, emotions or behavior?

- a) Yes
- b) No

12) At any time DURING THE PAST 12 MONTHS, did this child receive **behavioral intervention for any developmental delay (e.g. Autism, ASD, Asperger's Disorder or PDD)**, such as training or an intervention that you or this child received to help with his or her behavior (like Applied Behavior Analysis (ABA))?

- a) Yes
- b) No

13) Is this child CURRENTLY taking medication for ADD or ADHD?

- a) Yes
- b) No

14) Is this child CURRENTLY taking medication for anxiety or depression?

- a) Yes
- b) No

Questions about your child's special needs care

15) Does your child receive specialized care or services outside of the school day?

- a) Yes
- b) No → SKIP to 17

16) DURING THE PAST 12 MONTHS, how difficult was it to get the specialized care or services that your child needed?

- a) Very Difficult
- b) Somewhat Difficult
- c) Somewhat Easy
- d) Very Easy

17) DURING THE PAST 12 MONTHS, has this child received any treatment or counseling from a **mental health professional**? Mental health professionals include psychiatrists, psychologists, psychiatric nurses, and clinical social workers.

- a) Yes
- b) No, but this child needed to see a mental health professional
- c) No, this child did not need to see a mental health professional → SKIP to question 19

18) How difficult was it to get the mental health treatment or counseling that this child needed?

- a) Very Difficult
- b) Somewhat Difficult
- c) Somewhat Easy
- d) Very Easy

19) DURING THE PAST 12 MONTHS, was there any time when this child needed health care but it was not received? By health care, we mean medical care as well as other kinds of care like dental care, vision care.

- a) Yes → go to 20, no SKIP
- b) No → SKIP to 22

20) If yes, which types of care were not received? Mark (X) ALL that apply.

- a) Medical Care
- b) Dental Care
- c) Vision Care
- d) Hearing Care
- e) OT, PT, and/or Speech Therapy

21) Did any of the following reasons contribute to this child not receiving needed services? Mark (X) All that apply.

- a. This child was not eligible for the services.
- b. The services this child needed were not available in your area.
- c. There were problems getting an appointment when this child needed one.
- d. There were problems with getting transportation or child care.
- e. There were issues related to cost.
- f. I was told my child's behavior was too challenging to continue receiving services.
- g. Other _____ please specify.

22) DURING THE PAST 12 MONTHS, how often were you frustrated in your efforts to get services for this child?

- a) Never
- b) Sometimes
- c) Usually
- d) Always

23) Has this child EVER had a special education or early intervention plan? Children receiving these services often have an Individualized Family Service Plan (IFSP) or Individualized Education Plan (IEP).

- a) Yes

b) No →Skip to 26

24)How old was this child at the time of the FIRST plan? __YEARS __MONTHS

25)Is this child CURRENTLY receiving services under one of these plans?

- a) Yes
- b) No

Questions about your experiences with your child's healthcare and service providers

26)Is there a place that this child COMMONLY goes when he/she needs routine pediatric care, such as a check-up?

- a) Yes
- b) No

27)Where do you USUALLY take this child when he or she is sick or you need advice about his or her health?

- a) Doctor's Office
- b) Hospital Emergency Room
- c) Hospital Outpatient Department
- d) Clinic or Health Center/ Urgent Care
- e) Retail Store Clinic or "Minute Clinic"
- f) School (Nurse's Office, Athletic Trainer's Office)
- g) Other (Please Specify)

28)DURING THE PAST 12 MONTHS, how often did you get as much help as you wanted with coordinating this child's special needs care?

- a) always
- b) usually
- c) sometimes
- d) never

29)DURING THE PAST 12 MONTHS, did a **case manager** help you arrange or coordinate this child's care among the different doctors or services that this child uses?

- a) Yes
- b) No SKIP to 13

30)How satisfied were you with your experience with your case manager?

- a) Very Satisfied
- b) Somewhat Satisfied
- c) Somewhat Dissatisfied
- d) Very Dissatisfied

31)DURING THE PAST 12 MONTHS, did a representative from **advocacy services** assist

you with advocating for your child's special needs?

- a) Yes
- b) No

32) How satisfied were you with your experience with your advocacy services?

- a) Very Satisfied
- b) Somewhat Satisfied
- c) Somewhat Dissatisfied
- d) Very Dissatisfied

33) What issues have you encountered with your child's special needs programs? (Please check all that apply)

- a) High staff turnover
- b) Could not find high-quality care
- c) Too expensive
- d) Building did not have right equipment
- e) Inexperienced/untrained staff
- f) Building not accessible
- g) Hours did not match my family's needs
- h) Unable to meet my child's needs
- i) Facility is too hard to get to
- j) Program would not take my child because of needs
- k) No access to medical professionals to provide support for child care staff
- l) Other (please specify)

Questions about providing for your child's services

34) DURING THE PAST 12 MONTHS, have you or other family members... (Please check all that apply)

- a) Left a job or taken a leave of absence because of this child's health or health conditions?
- b) Cut down on the hours you work because of this child's health or health conditions?
- c) Avoided changing jobs because of concerns about maintaining health insurance for this child?

35) To what extent does your health insurance allow your child to receive services that meet their special needs?

- a) My child's needs are fully met.
- b) My child's needs are partially met.
- c) My child's needs are not met at all.

36) Where do you go to receive with information about where and how to obtain help for your child's special needs or behavioral health? (Please check all sources of information that you use)

- a) 211 Broward
- b) Doctor
- c) Case Manager

- d) Social Service Agency (other than Case Manager)
- e) School
- f) Friends/Family
- g) Other Parents
- h) Advocacy Groups
- i) Other _____

PART 3: Caregiver Perceptions of System of Care

Instructions: *Please read each sentence below and select the response that most closely matches your opinion related to the services your child has received.*

Questions related to identification, screening, assessment or referral source

	Strongly Agree	Agree	Disagree	Strongly Disagree	Do Not Understand/ Not Applicable
It was hard to find a professional to make a diagnosis for my child.					
I did not know who to call or where to go for help for my child.					
My child's special need was not identified until they entered the school system.					
I used 2-1-1 Broward Information and Referral Services to get help for my child.					
Family members/elders thought there was no problem with my child.					
A doctor or medical professional told me that there was nothing wrong with my child.					
A doctor or medical professional gave my child a different diagnosis than the one they currently have.					
I did not realize anything was wrong with my child for some time.					
My husband/wife or partner resisted taking our child for help.					

Please read each sentence below and select the response that most closely matches your opinion related to the services your child has received from providers outside of the School System.

Questions related to community services, satisfaction with services, and customer experience

	Strongly Agree	Agree	Disagree	Strongly Disagree	Do Not Understand/ Not Applicable
Service Providers					
. The needs of my child are being adequately addressed by their service providers.					
. My child’s service provider is knowledgeable about my child’s unique needs.					
. My child’s service providers are willing to answer my questions about my child’s care.					
. The locations of services for my child are convenient.					
. The hours that services are available are convenient.					
. My child’s service provider treats me as a partner in providing my child’s care.					
. Professionals were courteous and listened to my concerns about my child.					
. My child’s best interests are the 1 st priority of the service providers.					

Please read each sentence below and select the response that most closely matches your opinion related to the services your child has received within the School System.

Schools' efforts to partner with caregivers

	Strongly Agree	Agree	Disagree	Strongly Disagree	Do Not Understand/ Not Applicable
My child's school offers afterschool care to meet my child's needs.					
My child's school gave me information about organizations that offer support for parents of students with disabilities resources/programs.					
My child's school treats me as partner.					
My child's school provides information on agencies that can assist my child in the transition from school.					
My child's evaluation report is written in terms I understand.					
My child's school gives me information regularly about my child's progress on IEP goals.					
My child's school offers parents training about special education issues.					

Transition support

	Strongly Agree	Agree	Disagree	Strongly Disagree	Do Not Understand/ Not Applicable
My child transitioned into the school system's special education program from early childhood care without a break in services.					
I was provided information on transitioning my child to the next level of service (e.g., from elementary to middle school, from middle to high school).					
My child transitioned from to special education (K-12) to adulthood without a break in services.					
My child received all the supports for transition listed in our IEP/IFSP.					

28) Has your child received financial education or employment support training to assist with transition to adulthood?

- a. Yes
- b. No

29) Has your child used Vocational Rehabilitation (VR) services?

- a. Yes
- b. No

30) Was your child referred to post-secondary educational options (i.e., colleges or technical programs)?

- a. Yes
- b. No

31) In general, were you satisfied with the help you received when transitioning your child to their next level of service?

- a. Very Satisfied
- b. Somewhat Satisfied

- c. Somewhat Dissatisfied
- d. Very Dissatisfied

Caregiver advocacy and support experience

	Strongly Agree	Agree	Disagree	Strongly Disagree	Do Not Understand/ Not Applicable
I know what to do if I disagree with some of the services my child is being provided.					
I have a support network to help me make important decisions about my child's educational/ medical needs.					
I am aware of my rights when advocating for my child's needs.					
Providers have respect for my cultural heritage.					
It was difficult to understand how special education systems work.					
It was difficult to understand how the medical and social service systems work.					
I faced discrimination from professionals or providers because of my race or ethnicity.					
I know how to access an advocate if I need one.					
Teachers or providers treated my child's problems differently because of their race or ethnicity.					
Teachers or providers thought my child's problems were due to another language being spoken at home.					
Information is provided to me in a language that I can understand.					
Providers have staff available that understand my culture.					

PART 4: Need for Services

Please select the response below that best describes your experience with each of the services listed below during the LAST 12 MONTHS.

Services	Used Service	Needed Service but could not access	Unaware of this service
211 Broward / Information & Referral			
Advocacy			
After school care			
Audiology /Hearing Therapy			
Behavioral Analysis (ABA)			
Behavioral Health Therapy			
Care Coordination			
Case Management Services			
Child Day Care/ Head Start			
Cognitive Therapy			
Communication Devices			
Dental Care			
Early Intervention			
Parent/Caregiver Support Education & Training			
Financial Education			
Home Health Care			
Individual Counseling			
Job Skills Training			
Language/ Translation Services			
Legal Services			
Medical Equipment			
Medical Services			
Medications Co-Payment Assistance			
Nutrition Services			
Occupational Therapy			
Physical Therapy			
Psychological Assessment			
Psycho-Social Evaluation			
Residential Services/ Group Home			
Respiratory Services			
Respite Care/ In-home Relief for Caregiver			
Screening Services			
Social Security Benefits Planning (SSI/SSDI)			
Speech Therapy			

Support Groups			
Transportation			
Job / Employment Coach			
Social Security Administration Youth Work Incentives			
Other:			

Part 5: Questions about you and your family

- 1) What is your ZIP code? _____
- 2) What is your age?
 - 18 to 25
 - 26 - 35
 - 36 - 45
 - 46 - 55
 - 56 – 64
 - 65 or over
- 3) What is your sex?
 - a) Male
 - b) Female
- 4) Are you Hispanic/Latino?
 - a) Yes
 - b) No
- 5) Please select your race (check all that apply).
 - a) White/Caucasian
 - b) Black/African American
 - c) Native American
 - d) Asian/Pacific Islander
 - e) Other
- 6) Which languages are spoken in your home? (check all that apply).
 - English
 - Spanish
 - Creole
 - Other: _____
- 7) Which of the following best describes your yearly household income?
 - Less than \$5,000
 - \$5,000 - \$14,999
 - \$15,000 - \$24,999

- \$25,000-\$49,999
- \$50,000-\$75,000
- \$75,000-\$100,000
- \$100,000+

8) Are you currently working? Yes, Full-time, Yes, Part-time No

9) How many children live in your household?

- a) 1
- b) 2
- c) 3
- d) 4
- e) 5 or more

10) Do you have more than one child with a disability or special need?

- a) YES
- b) NO

11) Are you currently married or living with a partner?

- a) YES
- b) NO

12) Is there another adult living in your household?

- a) YES
- b) NO

13) What level of education do you have?

- 8th grade or less
- Some high school
- Completed high school or GED
- Some college
- College graduate
- Vocational or technical training
- Advanced or other degree

APPENDIX C

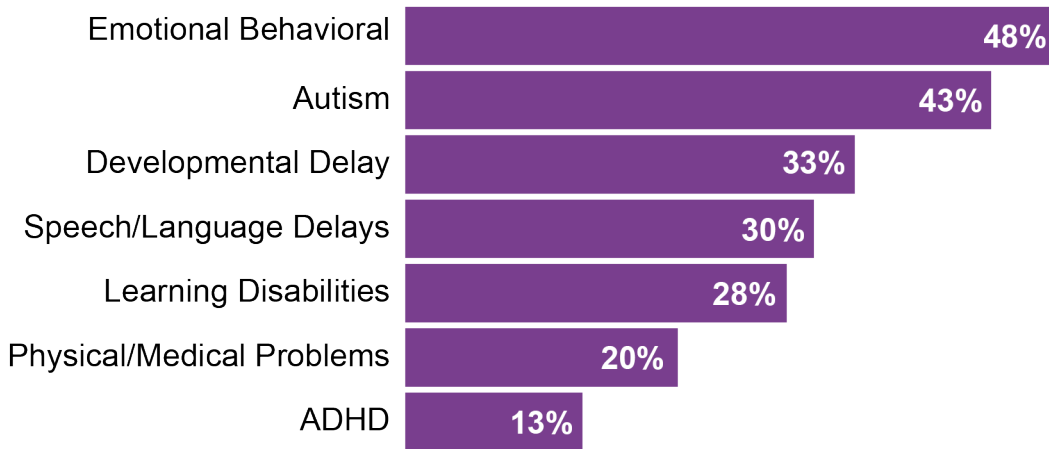
Focus Group Methodology and Guide

A total of 7 focus groups were conducted with various stakeholders. A description of the participants is summarized below. The guide used to facilitate the focus groups is also provided.

Parent Focus Group Participants

A total of 40 mothers and fathers, 35 women and 5 men, participated in four focus groups between November and December 2018. One third were White, one third were Black, and one fourth were Hispanic. A majority (83%) were between the ages of 30 and 49. Six parents had more than one child with special needs. Children's ages ranged from 5 to 23 years old. The most common diagnosis among the children was emotional and behavioral problems followed by autism and developmental delays. Many children had multiple diagnoses.

Figure 6: Children's Special Needs by Type



Provider Focus Group Participants

Fourteen (14) providers recruited by the CSC participated in a focus group on December 10, 2018. Two represented the Broward County Public Schools system and the remaining 12 were from non-profit service agencies and advocates working with children with special needs and their families including the Advocacy Network on Disabilities, the Center for Hearing and Communication, Broward Children's Center, Career Source Broward, 2-1-1 Broward, JAFCO, Arc Broward, Henderson Behavioral Health and the YMCA of South Florida.

System of Care Focus Group Participants

Five individuals participated in the System of Care focus group conducted on December 6, 2018. Participants were invited by CSC and represented county and state and county level agencies including Career Source, Broward, Broward County Transit, Children's Diagnostic

& Treatment Center (CDTC) Early Steps, the Agency for Persons with Disabilities, and the Broward County Community Partnership Division.

**FOCUS GROUP GUIDE
CHILDREN’S SERVICES COUNCIL SPECIAL NEEDS ASSESSMENT**

Parent/caregiver socio-demographic information

Gender:

Male ___ Female ___

Race/ethnicity:

White-non Hispanic ___

Black/African American ___

Asian/Pacific Islander ___

Native American ___

Hispanic ___

Multiracial ___

Age:

18 or less ___ **19-29** ___ **30-39** ___ **40-49** ___ **50+** ___

Relationship to child:

Parent (Mother or Father) ___

Grandparent (Grandmother or Grandfather) ___

Sibling (Brother or Sister) ___

Other Relative (e.g., Aunt or Uncle) ___

Legal Guardian ___

Foster Parent ___

Questions about your child

Age: _____

Gender:

Male ___ Female ___

Diagnosis (check all that apply):

1. Developmental Delay ____
2. Emotional/Behavioral Problems ____
3. Learning Disability ____
4. Physical/Medical Problems ____
5. Speech/Language Delays ____
6. Other (please specify) _____

QUESTIONS

Diagnosis:

1. What would a parent of a child who has just been diagnosed with a special need want to know about his/her immediate future?
 - What is the most common piece of information/advice a parent receives after diagnosis?
 - What critical information is usually left out? What else would you like to know?
 - Has anyone explained what the diagnosis means and what options are available [to the point of you feeling that you have full understanding]?
2. What types of supports are most needed at this time?
 - a. Child
 - b. Family (care to the caregiver)
 - c. To what extent are/were these supports offered to you and by whom?

Accessing Services and supports after diagnosis:

3. What would it look like if your child was receiving all the services he/she needs to be successful and/or independent? OR What would it take for you to say: I am happy with services and supports my child is receiving right now?
 - a. What role would doctors, specialists and teachers play?
 - b. How should they be communicating with each other and coordinating their work?
 - c. How would they be involving you and your child in the planning and decision-making?
 - d. What is it like for you and your child right now?
 - e. What is working well?
 - f. What do you need that you are not getting? What needs are not being covered?
4. What community resources that might better equip your child to be successful have you been connected to [i.e.; boys and girls clubs, scouting, etc.]?
 - a. What resources are there to help you learn how to parent a child with special needs?

Barriers to accessing services

5. How easy or hard is it for you to get the services your child needs?
 - a. What barriers are you facing to help your child be successful and/or independent?

6. Do you feel you face the same, fewer or more barriers/challenges because of
 - a. Where you live?
 - b. What your race/ethnicity is?
 - c. What language you speak?
 - d. Immigration status?
 - e. Economic status?
 - f. Other reasons?

Advocacy and supports

7. How prepared do you feel to advocate for your own child and be proactive?
 - a. How well do you know your rights?
 - b. Who do you go to for help when you need advocate to get what your child needs? Who are your strongest allies?
 - c. What would you need in order to be a more effective advocate for your child and family?

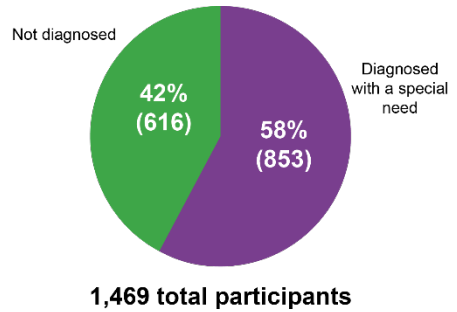
8. Do you have a peer mentor who [1] has gone through what you are going through, [2] understands how the system[s] work?
 - a. Who is this person/organization?
 - b. How did you find him/her?

Recommendations for system's improvements

9. What are the main recommendations you would give to those in charge of the system of care for your child?
 - Which ones are most likely to be acted on?
 - which ones are not? Why?

APPENDIX D: Responses from Caregivers of Children without a Diagnosis

In total, 1,469 surveys were collected from caregivers of youth who live and receive services in Broward County. Participants came from a variety of backgrounds. Of these respondents, 616 caregivers reported that their child had not been diagnosed with a disability or a special need. The demographic information that follows represents the demographics of the youth whose caregiver identified that they had been not been diagnosed with a special need (i.e., from the 616).



The majority of the participants who provided race/ethnicity information identified their child as White (47%), Hispanic/Latino (38%), and Black (37%). Other self-reported ethnicities included Asian and Native American. Fifty-one percent of participants who reported the sex of their child with special needs were caregivers of boys, while 27% were caregivers to girls with special needs. Sixteen percent of the sample chose not to answer questions on the sex, race and ethnicity of their child. The average age of the caregiver's child with special needs was about 10.3 years.

Participants who reported their child did not receive a diagnosis lived in 54 different zip codes, mostly in Broward County, but a few participants lived in Miami-Dade or Palm Beach. The most commonly reported zip codes were 33024, 33065, 33073, 33311, 33025, 33023, 33313, 33021, 33063, 33027, 33064, 33325, 33328.

Figure 7. Child Race Distribution

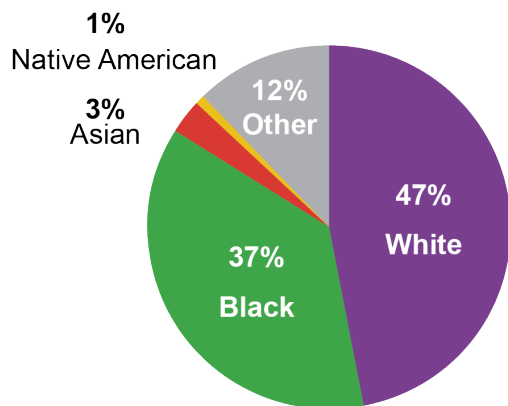


Figure 8. Child Ethnicity

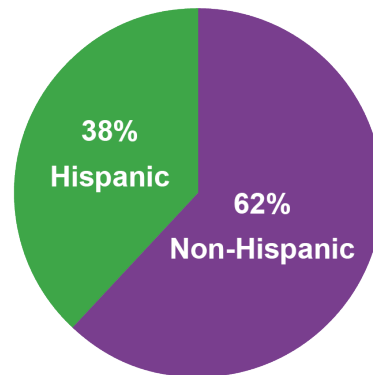
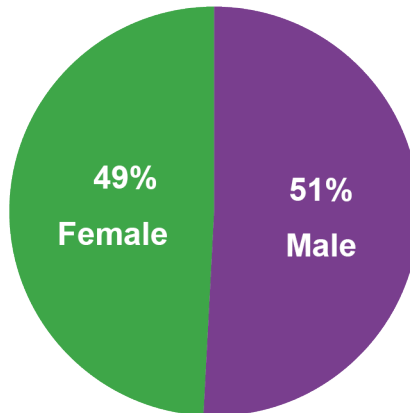
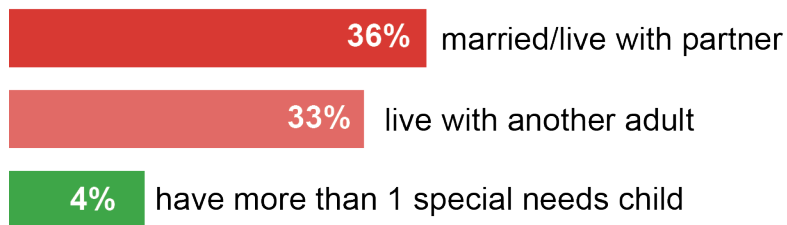


Figure 9. Child Gender



With regard to the caregivers themselves, only 36% of the caregivers reported being married or living with a partner, and 33% reported living with another adult. Only 4% percent of caregivers indicated that they had more than one child with a special need.

Figure 10. Caregiver Descriptors (N = 616)



Eighty three percent of caregivers were female, and the majority were between the ages of 36-45 (57%) or 46-55 years of age (32%).

Figure 11. Parent/Caregiver Gender

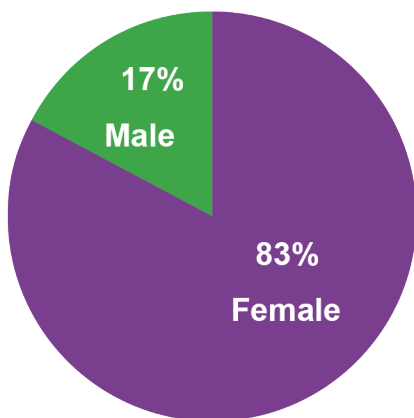
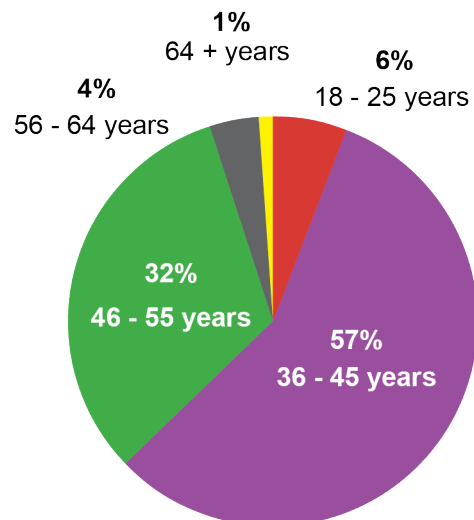


Figure 12. Parent/Caregiver Age



The majority of the caregiver participants who provided race/ethnicity information identified as White (49%) and Non-Hispanic/Latino (64%). Other self-reported ethnicities included Asian and Native American. Most respondents (83.70%) indicated that they spoke English at home.

Figure 13. Caregiver Annual Income Distribution

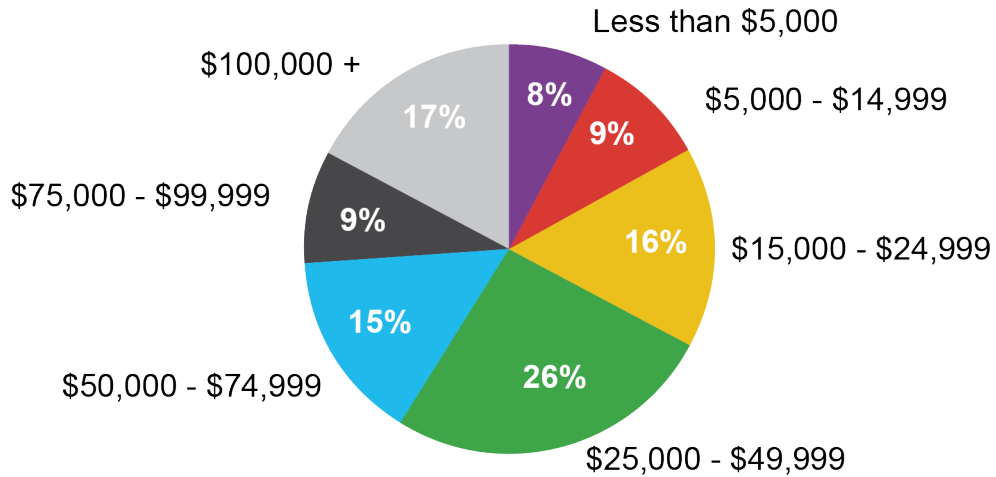


Figure 14. Caregiver Employment Status

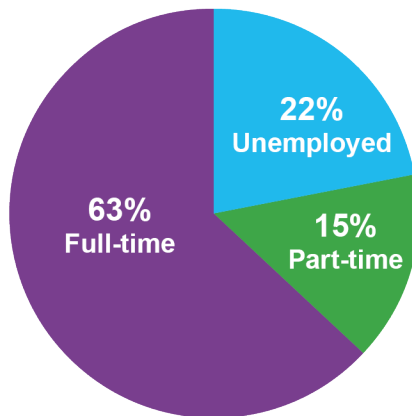
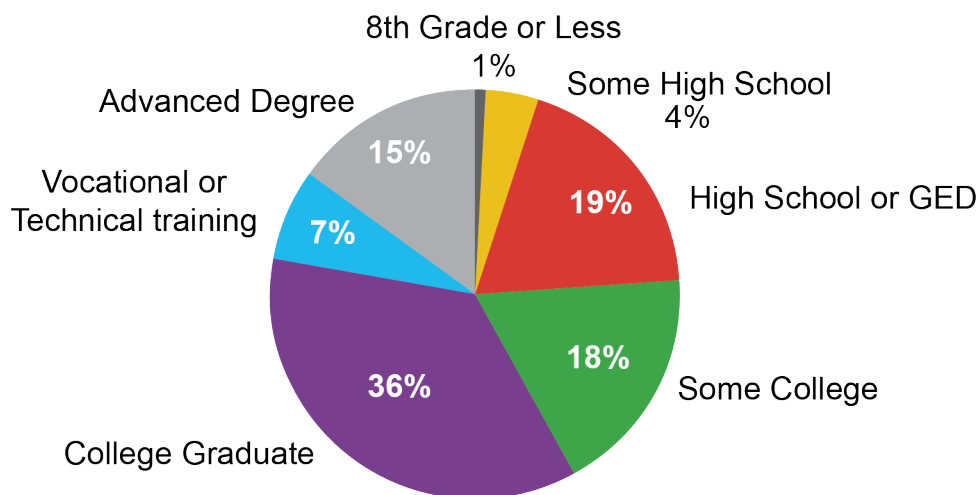


Table 4. Languages Spoken at Home

	N	Percent	Percent of Cases
English	283	65.5%	83.7%
Spanish	90	20.8%	26.6%
Creole	24	5.6%	7.1%
Other	35	8.1%	10.4%

Caregivers came from a variety of economic and educational backgrounds, with the most commonly reported income bracket being between \$25,000 and \$49,999 and being college graduates. The majority of caregivers were employed either full-time (63%) or part-time (15%). Only 4% percent of the sample reported receiving Social Security Benefits for their child.

Figure 15. Caregiver Education



Caregiver Perceptions

First, caregivers of children who reported their child was not given a diagnosis were asked to respond to a series of questions related to their experiences. It is important to note that the possibility exists that these children do indeed have a diagnosis or may have actually been diagnosed by a provider. That being said, the caregivers responding to these questions reported their child did not have a diagnosis. This might be because the child has not been diagnosed yet but does actually have a special need, the child truly does not have a diagnosis, or the parent does not realize/is not aware their child has been diagnosed with a special need. About 10% of the sample reported that their child had

either an IEP or IFSP at one point, with 4% reporting that their child is currently receiving services under an IEP or IFSP. The caregivers reported that average age of first IEP being 5.6 years. Taken together, this indicates that either some of the caregivers may not have understood that their child had a diagnosis or that they are not actually sure what an IEP is. It is also possible that a child was given an IFSP without a diagnosis, but then a diagnosis was never actually recorded.

Access to Care

Caregivers were asked a series of questions about accessing services and health care for their children. The majority of caregivers (87%) reported they do indeed have a place to take their child to access routine health care, with 83% reporting that they take their child to a doctor's office. Caregivers were also asked if a doctor or other health care provider asked them if they had concerns with regard to their child's learning, development or behavior. About 18% of parents responded that they had been asked about their concerns, the remaining 81% responded no. About 56% of caregivers agreed that a doctor or other medical professional had told them there was nothing wrong with their child; 19% disagreed with this statement, while 25% of the sample reported that this statement did not apply to them. When asked if professionals were courteous and listened to their concerns, 68% of caregivers agreed, 8% disagreed with this statement, while 24% of the sample reported that this statement did not apply to them.

Only 7% of caregivers (n = 26) reported needing access to health care for their child but not receiving it. When these 26 caregivers were asked about which types of services were difficult to access, they reported most difficulty with receiving Dental care (30.8%) followed by Medical Care (23.1%), Vision Care (19.2%), Physical Therapy (PT), Occupational Therapy (OT), and Speech Therapy (7.7%), and Hearing Care (3.8%). Next, caregivers were asked how often they were frustrated in their efforts to get services for their child. The majority of the sample (73.6%) reported never, while 19.2% reported sometimes.

Caregiver Support

Caregivers were also asked questions about their support systems. The majority of parents (65%) agreed that they had access to a support network to help them make decisions about their children's medical and educational needs. About 16% disagreed with this statement, while 19% of the sample reported that this statement did not apply to them. In addition, the majority of parents (78%) that they were aware of their rights when advocating for their child's needs. About 13% disagreed with this statement, while 9% of the sample reported that this statement did not apply to them.

Approximately 20% of caregivers agreed, that they did not know where to go for help for their child; 66% disagreed and another 14% reported that this was not applicable to them. Only 11% of caregivers agreed that they used 2-1-1 Broward for information/referrals to get help for their child.

About 9% of caregivers agreed that their partner resisted in taking their child for help; 54% disagreed with this statement, while 37% of the sample reported that this statement did not apply to them.

Equity

Caregivers were also asked questions about their treatment and their interactions with providers when using the system of care. Only 9% of parents agreed that they had faced discrimination from providers because of their race or ethnicity and that teachers/providers treated them differently because of their child's race or ethnicity. The majority of respondents disagreed with these two statements (70% and 64% respectively). Eighty percent of caregivers reported that information was provided to them in a language they could understand; only 8% disagreed with this statement, while 12% reported that this statement did not apply to them. Sixty percent of caregivers reported that providers had staff that understood their culture; only 10% disagreed, while 30% of caregivers reported that this statement did not apply to them.

¹ World Health Organization, (2011). World Report on Disability. https://www.who.int/disabilities/world_report/2011/en/

² The state of the world's children 2006: excluded and invisible. New York, United Nations Children's Fund, 2005.

³ Source: U.S. Census Bureau, 2013-2017 American Community Survey 5-Year Estimates

⁴ Public Law 114-95

⁵ Ibid.

⁶ <https://sites.ed.gov/idea/regs/b/a/300.8>

⁷ <https://www2.census.gov/library/publications/2011/acs/acsbr10-12.pdf>

⁸ Boyle CA, Boulet S, Schieve L, Cohen RA, Blumberg SJ, Yeargin-Allsopp M, Visser S, Kogan MD. Trends in the prevalence of developmental disabilities in US children, 1997–2008. *Pediatrics* 2011;127:1034–1042

⁹ National Center on Birth Defects and Developmental Disabilities,, Centers for Disease Control and Prevention

¹⁰ Ibid.

¹¹ Kraus, L., Lauer, E., Coleman, R., and Houtenville, A. (2018). 2017 Disability Statistics Annual Report. Durham, NH: University of New Hampshire.

¹² Kraus, L., Lauer, E., Coleman, R., and Houtenville, A. (2018). 2017 Disability Statistics Annual Report. Durham, NH: University of New Hampshire.

¹³ <https://www2.census.gov/library/publications/2011/acs/acsbr10-12.pdf>

¹⁴ McFarland, J., Hussar, B., Wang, X., Zhang, J., Wang, K., Rathbun, A., Barmer, A., Forrest Cataldi, E., and Bullock Mann, F. (2018). The Condition of Education 2018 (NCES 2018-144). U.S. Department of Education. Washington, DC: National Center for Education Statistics. Retrieved 3/22/2018, from <https://nces.ed.gov/pubsearch/pubsinfo.asp?pubid=2018144>.

¹⁵ Ibid.

¹⁶ Ibid.

¹⁷ <https://www.childtrends.org/child-trends-5/5-things-know-racial-ethnic-disparities-special-education>

¹⁸ Ibid.

¹⁹ Ibid.

²⁰ Source: U.S. Census Bureau, 2013-2017 American Community Survey 5-Year Estimates

²¹ IDEA Section 618 Data Products: Static Tables, www.ideadata.org

²² KIDS COUNT Data Center, datacenter.kidscount.org, A project of the Annie E. Casey Foundation

²³ Ibid.

²⁴ Ibid.

²⁵ <http://bcps-esls.com>

²⁶ <http://www.fldoe.org/core/fileparse.php/7672/urlt/Broward18.pdf>

²⁷ Ibid.

²⁸ Ibid.

²⁹ <https://www.cscbroward.org/index.php/>

³⁰ <http://211specialneeds.org/faqs/>

³¹ U.S. Department of Health and Human Services. (2017). National Survey of Children's Health.

³² Wayne State University, Center for Urban Studies. (2017). Parent Survey Special Education for Students. Michigan Department of Education.

³³ Iland, E. D., Weiner, I., & Murawski, W. W., (2012). Obstacles Faced by Latina Mothers of Children with Autism. *Californian Journal of Health Promotion*, 10, 25-36.