

Children and Youth with Special Health Care Needs in Foster Care

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Introduction

In this brief, Child Trends examines the prevalence of children and youth with special health care needs (CYSHCN) in the foster care system. CYSHCN have—or are at increased risk for—chronic physical, developmental, or behavioral/emotional conditions.¹ This brief provides an overview of the literature on CYSHCN and their experiences in the foster care system, a detailed explanation of the methodology used for the current brief, an explanation of our findings, and a brief discussion of practice and policy implications.

Our findings suggest that children and youth's reasons for entering foster care, their experiences while in care, and their reasons for leaving care vary depending on whether they have an SHCN. The findings presented below represent the national data; additional information on all 50 states and the District of Columbia (DC) is available in Appendix A.

For our analysis, we utilized the Adoption and Foster Care Analysis and Reporting System (AFCARS) Foster Care File, which provides data on the characteristics and foster care experiences of children and youth who have spent at least one day in foster care during a given fiscal year. Although AFCARS does not identify children who have a special health care need (SHCN), per se, it does indicate whether children have physical, developmental, or emotional/behavioral disabilities; we used this information as a proxy for SHCN.¹

Key findings

- Children and youth with special healthcare needs (CYSHCN) comprise at least 24 percent of the foster care population and may require unique services and resources during their time in foster care.
- The proportion of children and youth in care identified as having a special health care need (SHCN) varies by state. Differences in states' policies and practices related to assessing children in foster care for SHCN and tracking this information in administrative data systems likely result in substantial underidentification of SHCN among children in foster care in some states.
- CYSHCN tend to enter foster care for different reasons than their peers without an SHCN. These include the following:

¹ For more information on what is included in AFCARS, please see page 5.

- Caretaker inability to cope
- Physical abuse
- Child behavior problems
- Abandonment or relinquishment
- Child disability
- Sexual abuse
- Drug or alcohol abuse by the child
- Parent death
- CYSHCN in foster care are more likely to:
 - Have experienced an adoption disruption
 - Have more than one removal episode
 - Experience greater placement instability
 - Spend significantly more time in care
- In addition, CYSHCN are *less* likely to achieve permanency (i.e., reunification with their family, adoption, guardianship, or living with a relative).

Literature Review

One in five children in the general population are diagnosed with an SHCN.

In the United States, one in five children are diagnosed with an SHCN.ⁱⁱ CYSHCN and their families require strong support to successfully navigate health care systems and other public institutions. For example, families with CYSHCN report more frequent medical care, and may accrue health care expenditures up to three times higher than children without SHCN.ⁱⁱⁱ However, despite the fact that most CYSHCN are insured, about one third of families with CYSHCN report inadequate insurance coverage.^{iv} Within the CYSHCN population, disparities in access to health care and other resources may make it more difficult for families to adequately care for their children. Caregivers of CYSHCN encounter financial stress, burdens related to care, and social isolation—often due to feeling that others did not understand their family situation and that they could not talk to doctors or physicians.^{xv} Some children and youth are more likely to be identified as having an SHCN: For example, adopted children and children in foster care are more likely to have an identified SHCN, when compared to their peers.^{vi}

Young people with an SHCN enter foster care at higher rates than their peers without one.

CYSHCN enter the foster care system at higher rates than their peers without SHCN, and tend to have different experiences within the system. Among children with substantiated maltreatment,² children with emotional disabilities were two times more likely to be placed in out-of-home care than children without disabilities.^{vii} CYSHCN are more likely to have longer foster care episodes and multiple placements. They also achieve permanency at lower rates than their peers in care without an SHCN.^{viii} While placement in a

² Not all cases that come into contact with the child welfare system are substantiated and not all children and youth enter foster care. A report can be unsubstantiated, meaning that no abuse or neglect was found. A report can also be substantiated, but a determination made that the child can safely remain in the home. When this happens, families are provided services to ensure that the child or youth is safe while in the home and to mitigate the risk for additional abuse or neglect to occur.

medical foster home³ or treatment foster home is considered to be the best placement option for children with an SHCN, a lack of certified medical foster homes or treatment foster homes means that many CYSHCN are placed in regular foster homes with foster parents who may have minimal training on caring for CYSHCN.^{ix} For some families, involvement with the child welfare system may present an additional barrier to receiving the specialized care they need. CYSHCN in foster care may experience gaps in insurance coverage because of changing providers and other administrative delays,^x inconsistent medical records,^x and placement instability, resulting in delayed health care and increased disparities relative to CYSHCN not in foster care.^{viii} While the child welfare system tries to ensure children's safety and well-being, caseworkers and foster parents often lack the resources to address complex health care needs.^{viii}

Foster parents of CYSHCN require more support and training than they currently receive to effectively care for CYSHCN.^{xi,x} Foster parents are typically required to find their own medical providers or use a provider selected by the child welfare agency for initial health screenings and assessments, and must receive approval from the child welfare system before proceeding with some health care decisions.^x Most children and youth in foster care qualify for and are insured through the Medicaid program.^{xii} However, many foster parents report difficulties finding providers who accept Medicaid or treat CYSHCN, due to their special health care needs and health histories.^x Foster parents also face hurdles to accessing health care information for their CYSHCN, and report insufficient communication between the child welfare and health care systems.^x For example, in one study, foster parents reported that health histories—including information regarding a child's development, health care, medication, and mental health—are not always provided.^x Of additional concern were the lack of continuity and consistency in medical and mental health care, including medication administration, for CYSHCN.^x

As with foster parents, many caseworkers struggle to understand the SHCN that affect children, and may require more support and training to identify and assist CYSHCN involved in the child welfare system.^{xiii} For example, one study found that caseworkers did not receive education or on-the-job training regarding the definition of Developmental Disability, leaving them to identify such conditions on their own.^{xiii} Below, we present findings on the unique experiences of children and youth with special health care needs in foster care.

Methodology and Data

Using AFCARS data from federal fiscal year (FY) 2018, we examined select demographic characteristics of CYSHCN in foster care at the end of the FY. To examine differences in how and when CYSHCN and their peers without SHCN exit foster care, we tracked a cohort of children and youth who entered foster care in FY 2014 over five years. For more information on our data and sample, please refer to Appendix A on page 18. Appendix B (page 20) includes more detailed information on state-level data for specific diagnoses.

AFCARS defines SCHN as the following:^{xiv}

1. Mental retardation⁴: Significantly subaverage general cognitive and motor functioning existing concurrently with deficits in adaptive behavior manifested during the developmental period that adversely affect a child's/youth's socialization and learning.

³ Medical foster homes refer to specialized foster homes that are designed to meet the special health care needs of children and youth.

⁴ The use of "mental retardation" is widely considered outdated language, and was supposed to be removed from all federal policy in 2010 and replaced with "intellectual disability." However, for clarity and consistency with the current AFCARS dataset, we've chosen to retain the language used in the dataset.

2. Visually or hearing impaired: Having a visual impairment that may significantly affect educational performance or development; or a hearing impairment, whether permanent or fluctuating, that adversely affects educational performance.
3. Physically disabled: A physical condition that adversely affects the child's day-to-day motor functioning, such as cerebral palsy, spina bifida, multiple sclerosis, orthopedic impairments, and other physical disabilities.
4. Emotionally disturbed: A condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree: An inability to build or maintain satisfactory interpersonal relationships; inappropriate types of behavior or feelings under normal circumstances; a general pervasive mood of unhappiness or depression; or a tendency to develop physical symptoms or fears associated with personal problems. The term includes persons who are schizophrenic or autistic. The term does not include persons who are socially maladjusted, unless it is determined that they are also seriously emotionally disturbed. The diagnosis is based on the Diagnostic and Statistical Manual of Mental Disorders Third Edition (DSM III) or the most recent edition." [Note: the current edition is DSM-V].
5. Other medically diagnosed condition requiring special care: *Conditions* other than those noted above which require special medical care such as chronic illnesses. Included are children diagnosed as HIV positive or with AIDS.

The AFCARS definitions are not as comprehensive as the HRSA definition⁵ of SHCN. These categories and differences in assessing and reporting policies in foster care may not capture all SHCN that qualify under the HRSA definition. The National Survey of Children with Special Health Care Needs captures a larger range of SHCN than AFCARS, but does not capture involvement in child welfare for children and youth who were not adopted. For example, AFCARS does not ask about medication, level of health care utilization, or ability to perform everyday tasks. Rather, it captures broad information about identified SHCN for children and youth in foster care.

Presentation of Findings

This section first compares demographic, point-in-time data on CYSHCN in foster care to the characteristics of children and youth in care without SHCN.⁶ Next, we provide data that compare the two groups' experiences in the child welfare system. All findings are meant only to provide a descriptive overview of CYSHCN in foster care. Such analyses do not allow us to draw conclusions about the causal relationships among SHCN, other child and family characteristics, and child welfare experiences.

Children in foster care

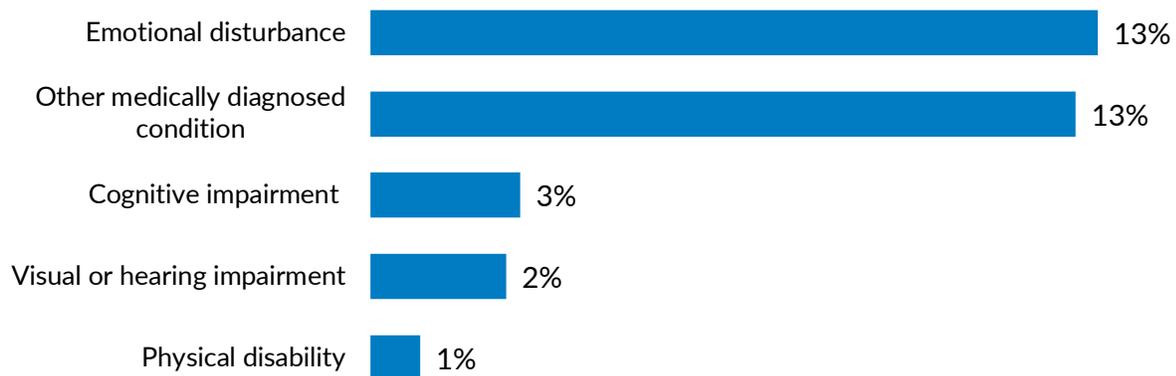
Child characteristics

Overall, 24 percent of children and youth under age 18 in foster care were identified as having an SHCN. The most common type of SHCN identified among children and youth in foster care are being emotionally disturbed (13%) or having some other medically diagnosed condition (13%).

⁵ HRSA defines individuals with special health care needs as "those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type of amount beyond that required by children generally."

⁶ These diagnoses can occur either before entry or after entry into foster care. We do not have information on the timing of diagnoses; therefore, we cannot make claims about how the diagnoses are associated with certain experiences while in foster care.

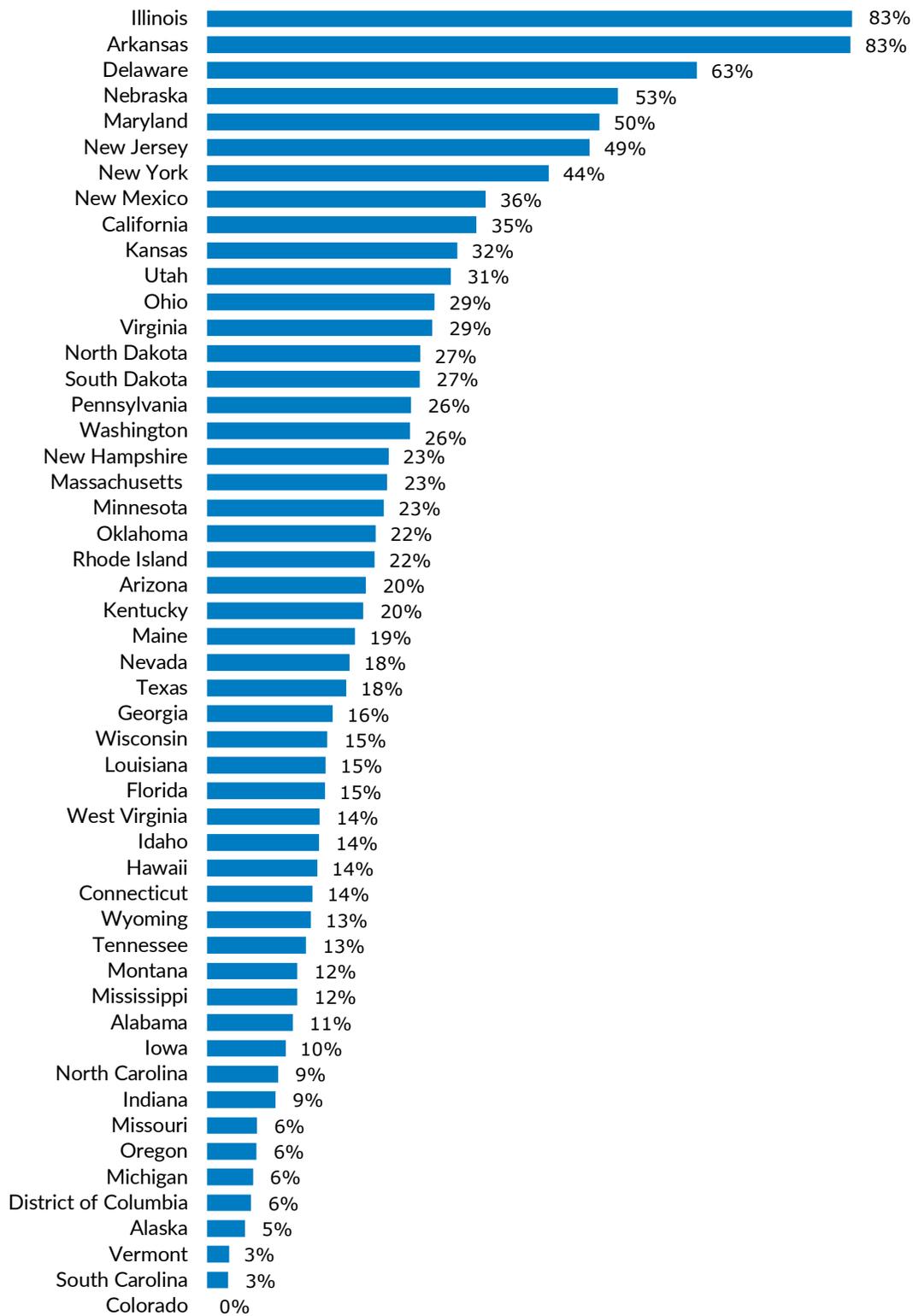
Figure 1. Type of identified SHCN: Children under age 18 in foster care at the end of FY 2018



Source: Child Trends analysis of data from the Adoption and Foster Care Analysis and Reporting System, FY2018

The proportion of children and youth in foster care with an identified SHCN varied widely across states (see Figure 2). Illinois, Arkansas, and Delaware had the largest shares of CYSHCN among their foster care population (83%, 83%, and 63%, respectively). Colorado, South Carolina, and Vermont reported the lowest proportion of CYSHCN in foster care (0%, 3%, and 3%, respectively). Three main reasons may account for this variation. First, states may vary in the accuracy with which they identify CYSHCN. State child welfare systems may assess children and youth differently, and may then report lower or higher levels of SHCN depending on how they assess children and youth in foster care. Second, even if states are aware of SHCN, they may vary in how they record SHCN in their data systems. State data systems differ and some may not be equipped to accurately reflect the assessment or identification of an SHCN; this may lead to low levels of reporting. Lastly, rates of SHCN may actually vary across states. This mirrors the rates of SHCN in the general population that vary across states.^{xv} Additionally, the threshold for entry into care may be different across states, leading to differences in rates of CYSHCN. States with a low rate of entry into foster care may have a higher proportion of CYSHCN. If the threshold for entry into foster care is very high, the population that enters care is more likely to be comprised of children with severe trauma that could rise to SHCN. States with alternative response systems (e.g., kinship diversion) tend to have relatively low entry rates. Family members in these states may not be equipped to care for children who need intensive health supports in their home, which could result in a foster care population comprised of a higher proportion of children with SHCN.

Figure 2. Prevalence of identified SHCN, by state



Source: Child Trends analysis of data from the Adoption and Foster Care Analysis and Reporting System Foster Care File, FY2018 V1

Older youth in care are more likely than their younger peers to have an identified SHCN (see Table 1). The mean age of CYSHCN in care is 9.7 years, compared to 6.9 years for those without SHCN. This may partially be due to the fact that many SHCN present themselves in older children and youth.^{xvi} Additionally, more assessments are completed the longer a child is in foster care, allowing more time for the child welfare system to identify an SHCN.

Males in foster care are more likely than their female counterparts to have an identified SHCN (see Table 1). This mirrors all CYSHCN, including those not in care: Of all CYSHCN in the general population, 58 percent are male and 42 percent are female^{xvii}. Differences in gender may be due to both biological and social constructs; for example, girls are less likely to exhibit externalizing behaviors.^{xviii} More information is needed on the role that gender plays in diagnoses.^{xix}

Black and Hispanic children and youth in foster care are significantly more likely than their peers in other racial/ethnic groups to be diagnosed with an SHCN (see Table 1). Within the foster care population of CYSHCN in each racial/ethnic group, 15 percent of Native American/Alaskan Native children and youth have an identified SHCN, as do 22 percent of Asian, 28 percent of Black, 17 percent of Native Hawaiian/Pacific Islander, 26% of Hispanic, 23 percent of multiracial, and 22 percent of White children and youth. Black children are overrepresented in the general population of CYSHCN.^{xx} Additionally, Black males (30%) and females (27%), Hispanic males (28%), and males of more than one race (25%) have the highest rates of SHCN identification among children in care.

Structural racism in the child welfare (e.g., report of abuse, investigation, and entry into care) and health care systems (e.g., access to health care, quality of health care) affects the likelihood of being diagnosed with an SHCN, the timing of that diagnosis, and how that diagnosis impacts foster care experiences. Structural racism within (e.g., placement of children) and related to (e.g., over-surveillance in communities of color) the child welfare system affects which families are reported to the child welfare system, the likelihood of a report being substantiated, and the length of time a child may spend in foster care.^{xxi} Additionally, structural racism within the health care system (e.g., the lower likelihood that medical providers will listen to patients of color) impacts the quality of care provided to children and families, as well as the ability of standardized health care screeners to properly identify SHCN among Black, Indigenous people of color (BIPOC), as these are largely designed for and evaluated on White children and youth.^{xxii} For example, many screeners are designed to reflect access to care for an SHCN. However, BIPOC experience additional barriers to medical care and might be unable to respond to the screener in the same way as a family without those barriers. This reflects a lack of access to health care rather than the presence (or lack) of an SHCN. Given the structural racism present in both the health care and foster care systems, BIPOC may not receive proper screening, diagnosis, or services for their SHCN. The findings of an identified SHCN by race/ethnicity presented above should not be removed from the context of the child welfare and health care systems. When working with CHSHCN, always consider the systems that may impact their care.

Table 1. Prevalence of identified SHCN among children in foster care at the end of FY 2018, by demographic characteristics

Child characteristics		Percentage identified with SHCN
Overall prevalence		24%
Age	Less than 3 years	14%
	3 to 6 years	16%
	7 to 12 years ***	27%
	13 to 17 years ***	38%
Gender	Male ***	26%
	Female	22%
Race/ethnicity	American Indian/Alaskan Native, non-Hispanic (NH)	15%
	Asian, NH	22%
	Black/African American, NH ***	28%
	Hawaiian/Other Pacific Islander, NH	17%
	Hispanic (any race) ***	26%
	More than one race, NH	23%
	White, NH	22%
Race/ethnicity unknown	17%	
Adoption history	Has not been adopted	24%
	Previously adopted	51%

Source: Child Trends analysis of data from the Adoption and Foster Care Analysis and Reporting System Foster Care File, FY 2018 V1

* Group members are significantly more likely than peers in other demographic groups to be diagnosed with SHCN ($p < 0.05$).

*** Group members are significantly more likely than peers in other demographic groups to be diagnosed with SHCN ($p < 0.001$). For example, youth ages 13 to 17 were more likely than children and youth of all other ages (0 to 12) to be diagnosed with an SHCN.

Table 2. Prevalence of identified SHCN among children in foster care, by gender and in combination with race and Hispanic origin

Race/ethnicity	Percentage of males identified with SHCN	Percentage of females identified with SHCN
American Indian/Alaskan Native, non-Hispanic (NH)	16%	13%
Asian, NH	25%	19%
Black/African American, NH	30%***	27%***
Hawaiian/Other Pacific Islander, NH	17%	16%
Hispanic (any race)	28%***	24%
More than one race, NH	25%*	21%
White, NH	24%	20%
Race/ethnicity unknown	18%	16%

Source: Child Trends analysis of data from the Adoption and Foster Care Analysis and Reporting System Foster Care File, FY 2018 V1

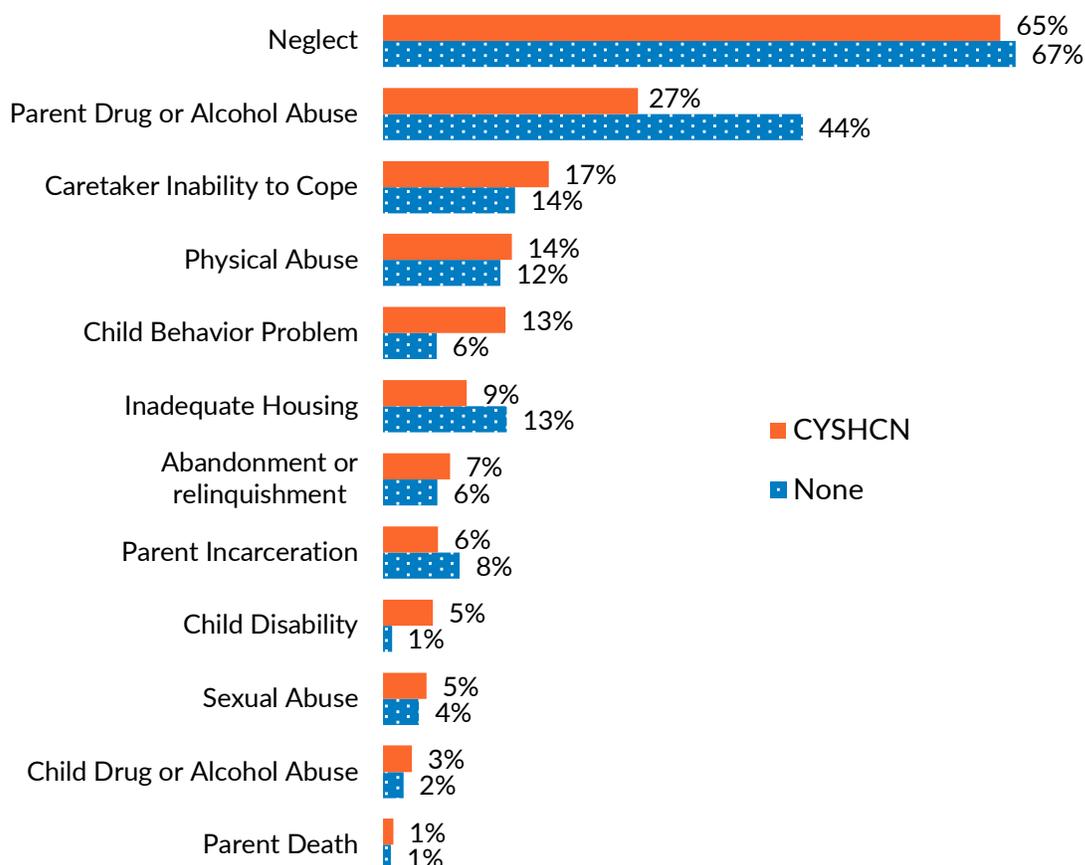
* Group members are significantly more likely than peers in all other groups to be diagnosed with SHCN ($p < 0.05$).

*** Group members are significantly more likely than peers in all other groups to be diagnosed with SHCN ($p < 0.001$).

Experience in the foster care system

CYSHCN in foster care are more likely than their peers without SHCN to have been removed from their homes for the following reasons: caretaker inability to cope, physical abuse, child behavior problems, abandonment or relinquishment, child disability, sexual abuse, drug or alcohol abuse by the child, and parent death.⁷ Entry reasons vary by the identification of an SHCN.

Figure 3. Percentage of children and youth entering foster care for various reasons, by SHCN status



Source: Child Trends analysis of data from the Adoption and Foster Care Analysis and Reporting System Foster Care File, FY 2018 V1

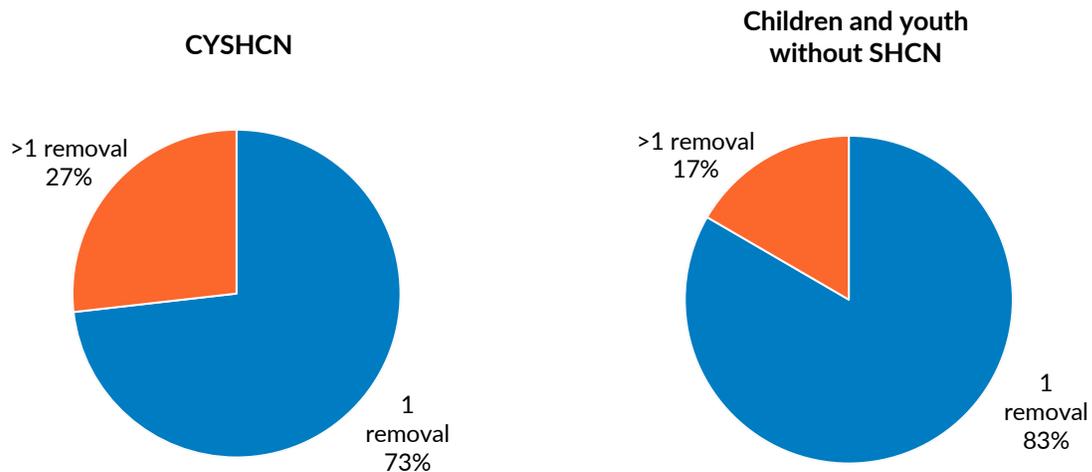
*** All differences between children with identified special health care needs and those without are statistically significant at the $p < 0.001$ level.

CYSHCN in foster care are more likely than their peers without SHCN to have been removed from their homes more than once (26.8% and 16.6%, respectively).⁸ These findings may indicate that children and youth with multiple removal reasons have more time for multiple assessments and thus a greater likelihood of being identified as having an SHCN.

⁷ Statistically significant at the $p < 0.001$ level

⁸ Statistically significant at the $p < 0.001$ level

Figure 4. Percentage of children and youth with 1+ removal, by SHCN status

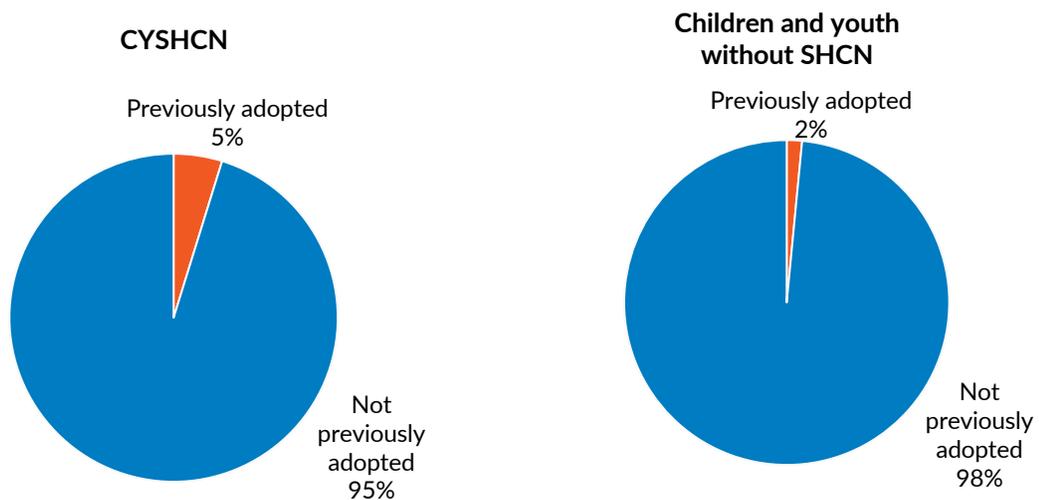


Source: Child Trends analysis of data from the Adoption and Foster Care Analysis and Reporting System Foster Care File, FY 2018 V1

*** All differences between children with identified special health care needs and those without are statistically significant at the $p < 0.001$ level.

CYSHCN in care are also more likely to have been previously adopted. This finding suggests that adoptive parents may need more resources and training to support CYSHCN to avoid disrupted adoptions.⁹ Additionally, prior to adoption, children are often assessed for an SHCN. This additional assessment may itself increase the chances of being identified as having an SHCN.

Figure 5. Percent of children and youth in care with a previous adoption



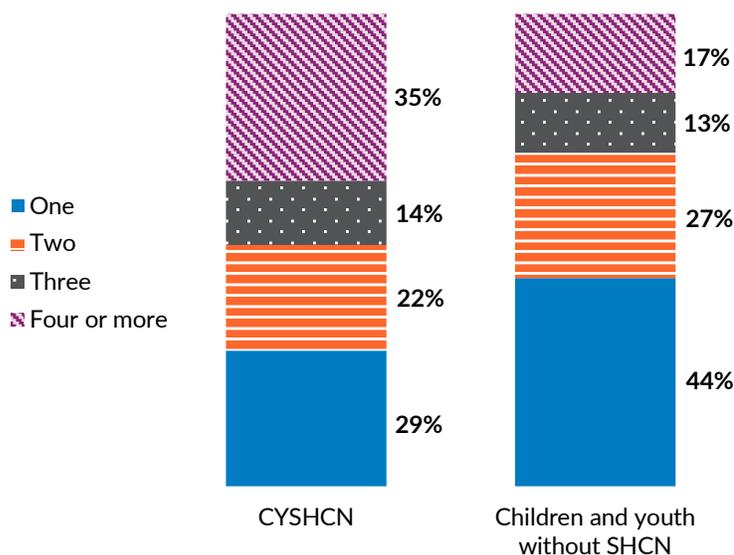
Source: Child Trends analysis of data from the Adoption and Foster Care Analysis and Reporting System Foster Care File, FY 2018 V1

*** All differences between children with identified special health care needs and those without are statistically significant at the $p < 0.001$ level.

⁹ Statistically significant at the $p < 0.001$ level

CYSHCN also face more placement instability than children and youth in foster care without SHCN.¹⁰ On average, CYSHCN had four placements during their most recent removal episode, compared to 2.4 placements for children and youth without SHCN.¹¹ This finding may be associated with the child's age and their length of time spent in care. Older youth who spend more time in foster care have an increased opportunity for an SHCN to be identified. This finding suggests that CYSHCN and their foster families may need additional resources, such as safe respite options (short-term placements meant to provide a break of a day or two, much like a sleepover with friends or grandparents for children and youth in the general population).^{xiii} CYSHCN may need a specialized placement to achieve placement stability. A focus on increasing the number of treatment or medical foster homes should be considered to decrease placement instability.

Figure 6. Number of placements since last removal



Source: Child Trends analysis of data from the Adoption and Foster Care Analysis and Reporting System Foster Care File, FY 2018 V1

*** All differences between children with identified special health care needs and those without are statistically significant at the $p < 0.001$ level.

To understand the differences between the length of time children and youth with and without SHCN spend in foster care, we tracked all young people who entered care in FY 2014 over a five-year period. For those who had exited care by the end of FY 2018, the average length of stay for CYSHCN was 18.0 months, compared to 15.6 months for those without SHCN.¹² CYSHCN were twice as likely to be in foster care after five years than their peers without SHCN (10% and 5%, respectively).¹³ These findings indicate that CYSHCN spend significantly more time in the foster care system than their peers without an SHCN. The findings may also reflect that the longer a child or youth is in foster care, the more opportunity they have to be assessed for an SHCN; or reflect differences in permanency options and availability of medical foster homes. To achieve placement stability, CYSHCN may need placement with a family that is specially trained to work with them.

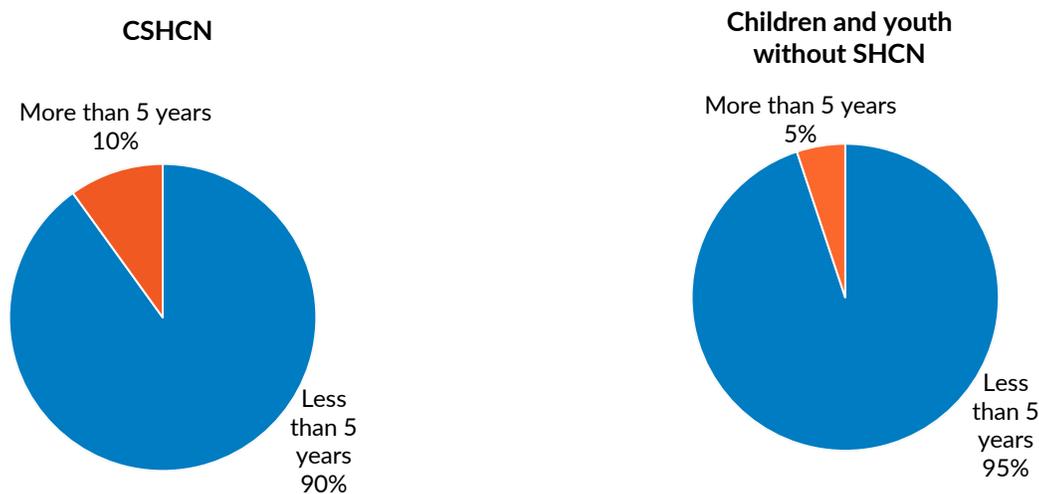
¹⁰ Statistically significant at the $p < 0.001$ level

¹¹ Statistically significant at the $p < 0.001$ level

¹² Statistically significant at the $p < 0.001$ level

¹³ Statistically significant at the $p < 0.001$ level

Figure 7. Percentage of children and youth remaining in care at the end of FY2018, among all children who entered care in FY 2014, by SHCN status



Source: Child Trends analysis of data from the Adoption and Foster Care Analysis and Reporting System Foster Care File, FYs 2014 V7, 2015 V5, 2016 V3, 2017 V2, and 2018 V1

*** All differences between children with identified special health care needs and those without are statistically significant at the $p < 0.001$ level.

Of the children and youth who exited care by the end of the five-year period, CYSHCN were less likely to achieve permanency¹⁴ than those without SHCN (84.8% and 92.9%, respectively).¹⁵ CYSHCN were more likely to exit as a result of emancipation (or age out of foster care),¹⁶ a transfer to another agency,¹⁷ a runaway status,¹⁸ or death.¹⁹ This finding indicates that CYSHCN may require specialized permanency services to increase their likelihood of being reunified or adopted. For example, CYSHCN benefit from specialized recruitment of foster or adoptive parents.^{xxiv} More information is needed to understand the services needed by and available for CYSHCN and their families.

¹⁴ "Permanency" includes the following discharge reasons: reunification, adoption, guardianship, and living with a relative.

¹⁵ Statistically significant at the $p < 0.001$ level

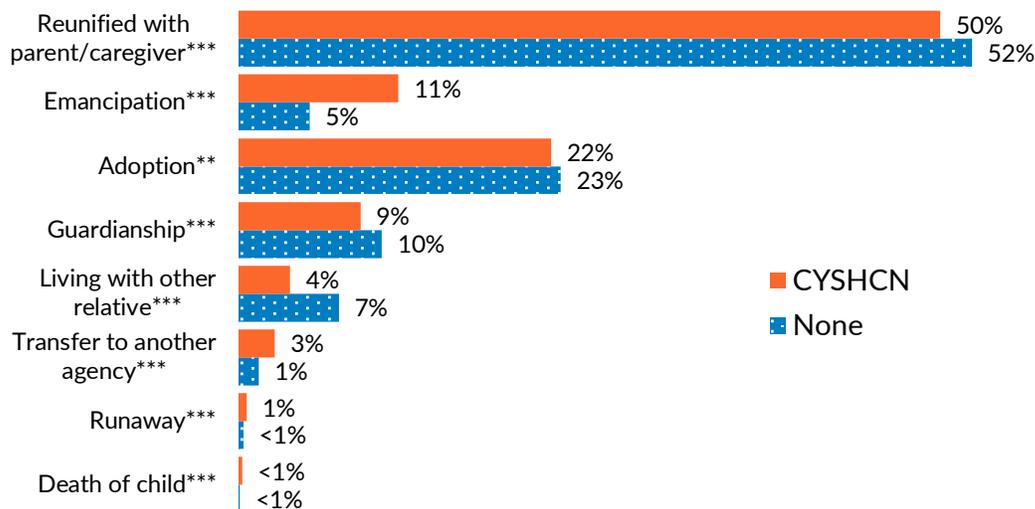
¹⁶ Statistically significant at the $p < 0.001$ level

¹⁷ Statistically significant at the $p < 0.001$ level

¹⁸ Statistically significant at the $p < 0.001$ level

¹⁹ Statistically significant at the $p < 0.001$ level

Figure 8. Discharge reason for those who exited care by FY 2018, among all children who entered care in FY 2014, by SHCN status



Source: Child Trends analysis of data from the Adoption and Foster Care Analysis and Reporting System Foster Care File, FYs 2014 V7, 2015 V5, 2016 V3, 2017 V2, and 2018 V1

** Differences between children with identified special health care needs and those without are statistically significant at the $p < 0.01$ level.

*** Differences between children with identified special health care needs and those without are statistically significant at the $p < 0.001$ level.

Discussion of Findings

Children and youth with special health care needs enter the foster care system, experience foster care, and ultimately leave foster care for different reasons, or under different circumstances, than their peers without SHCN. These unique characteristics and experiences require tailored services and supports for the child; their family of origin; and their foster family, preadoptive family, and adoptive family to help them navigate the foster care system and achieve and maintain permanency. While the most common SHCN for children and youth were emotional disturbances and Other diagnoses, we must consider the wide variation in needs and services across CYSHCN and tailor services that meet the needs of each child and family.

State variations likely highlight important differences in how states assess children, when they conduct the assessments, and how the information is captured in their data systems. While data quality limitations may account for some state variation (see page 18), the findings likely also reflect differences in state policies (e.g., policies that guide when and how assessment are conducted, when services are provided). For example, some states may provide more robust in-home prevention services and aim to bring only the highest-risk children into foster care. To fully understand such large variations in the proportions of CYSHCN in foster care, more information will be needed on state prevention services, assessment of SHCN, and policies on entry into foster care.

Our findings suggest that Black and Hispanic children and youth in care were more likely to have been identified with an SCHN than their peers in other racial/ethnic groups, which may highlight provider biases in the child welfare and health care systems. While the findings presented in this brief do not indicate when a child was identified as having an SHCN (e.g., prior to or after entering the foster care system), they do indicate key differences in identification of an SHCN and in foster care experiences. The

child welfare system may exacerbate disparities in identification of an SHCN, but there are other structural inequities that likely contribute. For example, inequities in access to health care, assessment and identification in schools, and other systems may contribute to the inequalities present within the child welfare system.^{xxv}

Lack of access to high-quality providers may compound trauma experienced by CYSHCN while in the foster care system. Family-centered health care²⁰ is the recommended approach to providing the best care for CYSHCN and their families.^{xxvi} However, families of color and families living in poverty are significantly less likely to receive family-centered health care.^{xxvii} Furthermore, families of color experience a lack of cultural competency (e.g., time spent with the child, respect for family values, listening to the child and family, and sense of partnership) among health care providers, which is associated with delayed or forgone care and dissatisfaction with the care provided.^{xxviii}

In addition to differences by race/ethnicity, we discovered differences in diagnoses based on gender and age among children and youth in foster care. Males are more likely to be diagnosed with an SHCN than females, and children over 12 are more likely than their younger peers to be diagnosed. While these differences mirror those seen among the general population, we should consider how having an SHCN may shape a child or youth's foster care experience. These differences underscore the importance of providing services to children and families that meet their specific developmental needs. Youth over age 12 are developmentally different than their younger peers and require different services. Families and caseworkers should be educated on adolescent brain development and distinguishing between developmentally appropriate behavior and problematic behavior for all behavioral health diagnoses.

Addressing differences in diagnoses based on race/ethnicity, gender, and age are critical to understanding how children and youth experience foster care. Males, children of color, and older youth experience foster care differently than their peers, and the child welfare system often fails to provide appropriate family-based placements for them. The system then moves away from providing permanency efforts and instead focuses on independent living, but all children and youth in foster care deserve a safe and stable home; it is the responsibility of the child welfare system to provide them one. These perceptions can be magnified for CYSHCN and require their caseworkers to provide specialized services and foster parent recruitment techniques. Medical foster homes are considered the ideal placement for CYSHCN in foster care, but the number of children and youth placed in these homes remains low.^{ix} More research is needed to better understand barriers to placement in medical foster homes and what resources foster parents need to provide high-quality care for CYSHCN, since placement stability is critical to helping children and youth in foster care achieve a permanent living arrangement.^{xxix}

CYSHCN may experience different challenges to achieving permanency than their peers in care without an SHCN. For example, CYSHCN in our sample were more likely to have a failed adoption, have multiple episodes in foster care, experience placement instability, and spend more time in care than children and youth in foster care without an SHCN. These experiences have previously been shown to lessen a child's likelihood of achieving permanency and increase their likelihood of experiencing adverse young adult outcomes.^{xxx} There is often minimal training and scarce communication provided to non-medical home foster parents on caring for CYSHCN.^x This includes training on medication compliance, developmentally appropriate rules and boundaries, communication, and supporting interactions with other children in the home. Without such information, foster parents are often left to navigate a complex child welfare and health care system with minimal supports, which may lead to placement instability. The length of time a child or youth spends in foster care may reflect the need to better educate potential foster parents about the unique needs of the children in their care. Another resource for foster parents caring for a CYSHCN is high-quality and reliable respite placements. The child welfare system must identify respite placement

²⁰ "An approach to planning, delivery, and evaluation of healthcare that is grounded in a mutually beneficial partnership among healthcare professionals, patients, and families."

options who can adequately meet the needs of CYSHCN.^{xxxi} These additional resources may allow more foster parents to provide long-term placements for CYSHCN.

CYSHCN who exit foster care were less likely to achieve permanency and more likely to be transferred to another agency or age out of care, relative to their peers without an SHCN. When a CYSHCN cannot be safely reunified with their family of origin, the child welfare system may turn its efforts to adoption, guardianship,²¹ or independent living. CYSHCN were less likely to be reunified or adopted, or to enter into a guardianship arrangement, than their peers without SHCN. This may indicate that biological families need additional or more tailored supports to work their case plan and provide a safe home for their child. The largest gap in permanency was for living with a relative, with 7 percent of children and youth without SHCN exiting to live with a relative, compared to only 3 percent of CYSHCN. This may be related to the foster care experiences (e.g., placement instability, length of stay) discussed above. Further research should focus on the relationship between placement stability and other foster care experiences and adoption outcomes for CYSHCN.

The current findings show that CYSHCN are more likely to experience adoption disruption, but we are unable to examine whether the diagnosis was made prior to or following adoption. Better data that capture the timing of diagnosis could illustrate the extent to which families understand the unique needs of their adopted child or youth. A better understanding of the cause of the adoption disruption may indicate the resources that are needed to prevent it. Increased post-adoption services may alleviate strain on adoptive placements and keep more children at home.^{xxxii}

When the child welfare system fails to achieve permanency for a children with special health care needs, they are likely to age out of foster care. Young people who age out of care experience an increased risk for several adverse outcomes. CYSHCN may experience additional hurdles, such as the need to transition to the adult health care system, unique needs and accommodations for their living situation, and employment and education assistance. More information is needed on the services and supports provided to CYSHCN at risk of aging out. Since older youth are more likely to have an SHCN and CYSHCN are more likely to age out of care than their younger peers, the system must better prepare youth to leave care and enter adulthood. Additional services and case planning may be required to address these needs.

Study Limitations

One limitation of this study is that states have different policies on when and how to conduct SHCN assessments and different reporting procedures on SHCN among children and youth in foster care. In addition, differences in prevention services, alternative response systems, and foster care entry rates likely explain some of the variation across states. However, the very low SHCN identification rates in some states suggests that certain states do a better job at identifying and reporting SHCN in their reporting systems. It is more probable that states with lower rates do not collect or report data on this measure. Without consistent reporting practices, we cannot grasp a full and accurate picture of the number of children and youth in care with an SHCN, or their experiences in the foster care system.

Another limitation related to data quality is that we were unable to track about 3 percent of the cohort for whom we examined discharge data. Some of this cohort was excluded from the sample due to inconsistent data (e.g., removal date) across FYs. Others without discharge information did not appear in subsequent FYs, making it impossible to know the circumstances around their exit from care. Another data quality limitation is that some statistically significant findings may be related to the large sample size. Differences may not be substantively significant when samples are very large.

²¹ In the foster care system, guardianship occurs when all rights and privileges of a parent are transferred to another caring adult who is appointed guardian. Guardianship refers to children and youth under age 18 who exit care to live with a new legally appointed guardian.

The definition of SHCN in AFCARS does not completely align with the definition of SHCN used to assess the prevalence in the general population. This means that comparisons to the general population should not be taken out of context and may be limited due to differences in what the data are capturing.

The final limitation, mentioned above, is the absence of information on the timing of the diagnosis. Data on diagnosis timing would shed light on how large of a factor SHCN diagnoses are in disrupted adoptions.

Conclusion

Despite limitations in how states identify and report CYSHCN, the current brief highlights the need to provide tailored, family-specific services to CYSHCN and their families, including their family of origin and their foster and adoptive families. CYSHCN enter foster care, experience foster care, and ultimately leave foster care under different circumstances than their peers in foster care without an SHCN. These differences require expertise from caseworkers, foster parents, and providers to ensure the safety and well-being of CYSHCN. More research is needed to fully understand the service array available to children and families with SHCN and which of those services leads to better outcomes for children and youth in foster care.

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Appendix A: Methodology

Data

The data used in this brief come from the foster care files of the Adoption and Foster Care Analysis and Reporting System for fiscal years (FY) 2014 through 2018. The AFCARS foster care file contains case-level demographic and case history data from state and tribal agencies on all children in foster care.

Sample

Snapshot data of children and youth in care at the end of FY 2018 include children and youth under age 18 for whom data are available on diagnoses of special health care needs.²² All measures reported in this brief reflect only those children and youth for whom data are available for the specified variable(s).

Exit data on the FY 2014 cohort reflect outcomes for children and youth under age 18 who entered foster care at any point in the fiscal year. If data on a child or youth are inconsistent across the five fiscal years we examined (e.g., if removal date changes from one FY to another), that child is excluded from this analysis.²³

Analysis

To understand the population of interest for these analyses, we began by comparing CYSHCN in foster care to those without an SHCN in foster care on several child-level demographics (e.g., race/ethnicity, gender, age). We then examined differences across the two groups' experiences in the child welfare system.

²² Diagnosis information is missing for 2.38% (10,048 records) of young people in foster care at the end of FY 2018.

²³ Records were inconsistent for 3.12% (8,191 children and youth) of the FY 2014 cohort. Of those whose records were consistent, 3.98% of children and youth did not have information on SHCN diagnoses.

Appendix B: State-level Diagnoses

State	Physical disability	Visually or hearing impaired	Cognitive impairment	Other medically diagnosed condition	Emotionally disturbed
United States	0.91%	2.48%	2.74%	12.90%	13.31%
Alabama	0.34%	0.38%	2.10%	2.70%	7.81%
Alaska	0.48%	0.40%	0.91%	2.02%	2.82%
Arizona	0.35%	4.86%	1.02%	12.31%	9.45%
Arkansas	0.19%	4.37%	1.02%	82.36%	6.02%
California	0.52%	8.50%	0.19%	24.10%	9.24%
Colorado	0%	0%	0%	0%	0%
Connecticut	0.59%	1.13%	1.77%	8.48%	5.02%
Delaware	1.56%	6.66%	10.62%	26.77%	46.46%
District of Columbia	0.29%	2.33%	0.44%	2.04%	1.31%
Florida	0.18%	0.10%	0.48%	1.62%	13.93%
Georgia	0.16%	0.44%	0.63%	5.86%	11.06%
Hawaii	0.76%	0.63%	0.38%	10.77%	3.23%
Idaho	0.39%	0.55%	0.39%	12.63%	6.45%
Illinois	5.36%	15.81%	41.19%	66.68%	47.05%
Indiana	0.16%	0.40%	0.81%	3.38%	5.81%
Iowa	0.72%	0.52%	1.29%	4.51%	5.10%
Kansas	1.68%	0.54%	1.51%	8.76%	26.07%
Kentucky	0.71%	1.04%	2.54%	5.46%	15.30%
Louisiana	1.56%	1.98%	1.78%	7.51%	8.96%
Maine	1.97%	0.29%	1.16%	5.10%	14.79%
Maryland	5.33%	2.22%	3.03%	22.81%	27.19%
Massachusetts	1.05%	1.54%	0.54%	11.61%	13.66%
Michigan	0.33%	0.27%	1.30%	4.15%	0.68%
Minnesota	0.66%	0.59%	4.91%	3.61%	18.60%
Mississippi	0.31%	0.53%	0.40%	4.68%	7.93%
Missouri	0.15%	0.11%	0.30%	3.06%	4.33%
Montana	0.38%	0.66%	1.34%	5.55%	7.15%
Nebraska	0.54%	1.24%	3.63%	25.75%	33.01%
Nevada	0.18%	0.33%	0.42%	1.69%	17.72%
New Hampshire	0.21%	0.64%	5.84%	10.90%	12.54%
New Jersey	2.73%	11.32%	4.89%	28.76%	22.44%
New Mexico	1.64%	1.15%	1.47%	18.94%	22.78%
New York	2.21%	1.51%	2.19%	18.28%	34.58%
North Carolina	0.79%	0.54%	0.78%	4.81%	3.92%
North Dakota	0.46%	1.63%	2.21%	7.23%	20.46%
Ohio	1.36%	1.49%	2.70%	11.26%	20.34%

State	Physical disability	Visually or hearing impaired	Cognitive impairment	Other medically diagnosed condition	Emotionally disturbed
Oklahoma	0.76%	0.90%	3.04%	12.76%	14.35%
Oregon	0.70%	0.54%	1.16%	4.28%	3.10%
Pennsylvania	1.11%	0.93%	1.57%	12.69%	15.35%
Rhode Island	0.52%	0.57%	1.46%	10.59%	14.82%
South Carolina	0.18%	0.18%	0.47%	0.65%	2.20%
South Dakota	0.72%	1.01%	1.01%	5.99%	24.33%
Tennessee	0.13%	0.06%	0.30%	8.41%	5.78%
Texas	0.76%	0.52%	1.28%	8.32%	11.15%
Utah	2.31%	1.34%	1.22%	14.41%	24.07%
Vermont	0.08%	0.32%	0.08%	0.64%	2.15%
Virginia	0.82%	0.59%	3.72%	7.28%	22.84%
Washington	1.43%	2.39%	0.78%	19.58%	8.55%
West Virginia	0.17%	0.34%	0.48%	2.59%	12.67%
Wisconsin	0.47%	0.61%	0.70%	7.29%	11.33%
Wyoming	0.37%	1.29%	1.75%	3.14%	7.66%

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