



# Children and Youth with Special Health Care Needs 2018 Outreach Survey Report

## Introduction

The Texas Department of State Health Services (DSHS) conducts an annual needs assessment to inform program practices and develop funding opportunities for children and youth with special health care needs (CYSHCN). Through an outreach survey, participants can provide demographic information and indicate needs for respite care, emergency preparedness, transition from childhood to adulthood, care coordination, and community inclusion. This report highlights key points from the 2018 survey results.

CYSHCN are individuals that “have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.”<sup>1</sup>

The 2018 Annual CYSHCN Outreach Survey for Young Adults and Families occurred April 17, 2018 through August 31, 2018. The Children with Special Health Care Needs (CSHCN) Systems Development Group developed the survey and staff in the DSHS Maternal and Child Health Epidemiology Unit (MCH Epidemiology) analyzed survey results. The CSHCN Systems Development Group distributed the survey in English and Spanish by mail and online. MCH Epidemiology tracked responses by zip code to ensure geographical representation of the state, including rural, urban, and border areas.

For the third year, young adults aged 18 years and older with special health care needs were invited to participate in the Outreach Survey. The Outreach Survey was sent to all CSHCN Systems Development Group contractors, distribution lists, and program partners, and the Texas Health and Human Services Commission’s CSHCN Services Program’s health care benefits clients to maximize outreach and provide assistance in overcoming response challenges. The program also promoted the survey through posts on the DSHS Facebook page.

Young adults ages 18 and older can be difficult to survey because of changes in services (e.g., medical, school, community, etc.) and residence. The number of young adult respondents increased from 2017 to 2018. Future efforts to encourage young adult participation will include targeted messaging and increased outreach to self-advocacy organizations.

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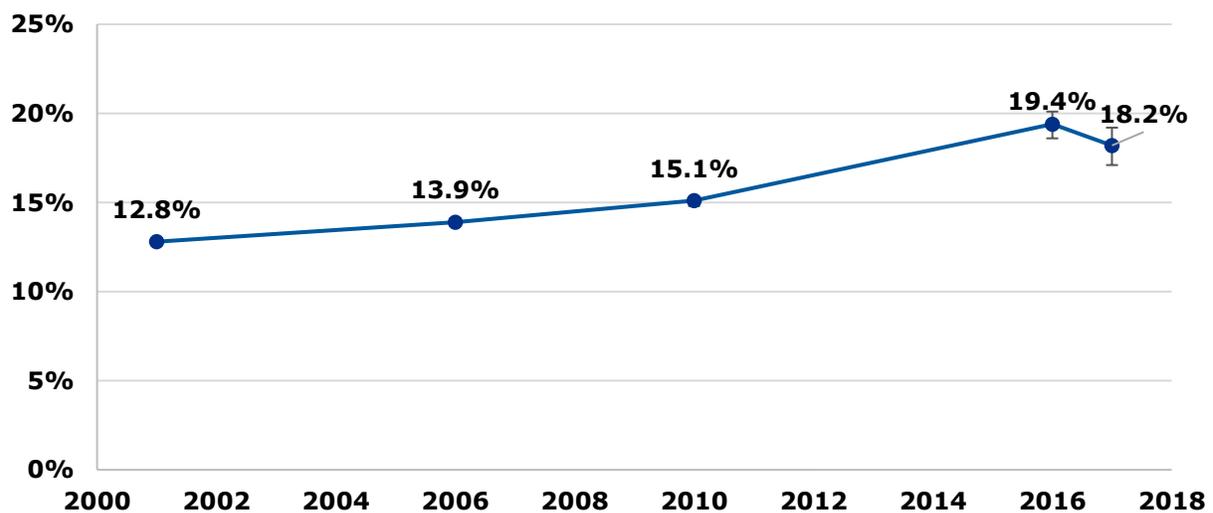
<sup>1</sup> McPherson, M et al. “A New Definition of Children with Special Health Care Needs,” *Pediatrics* Vol. 102 No. 1 July 1, 1998 pp. 137-139.



## Background

According to the 2016-2017 National Survey of Children’s Health survey, approximately one out of every six children in Texas have a special health care need (16.5%). This is slightly below the national average of 18.8%. The prevalence of CSHCN in the United States has ranged from 12.8% to 19.4% of all children age 0-17 years since 2001.

**Figure 1: Prevalence of Children with Special Health Care Needs in the United States, 2001-2017**



The CSHCN Systems Development Group supports family-centered, community-based strategies for improving the quality of life for CYSHCN and their families. The CSHCN Systems Development Group is part of the Maternal and Child Health Section within the DSHS. The purpose of the survey is to monitor Texas’ progress toward meeting performance measures and outcomes relevant to community inclusion, medical home, and transition to adulthood for CYSHCN and their families.

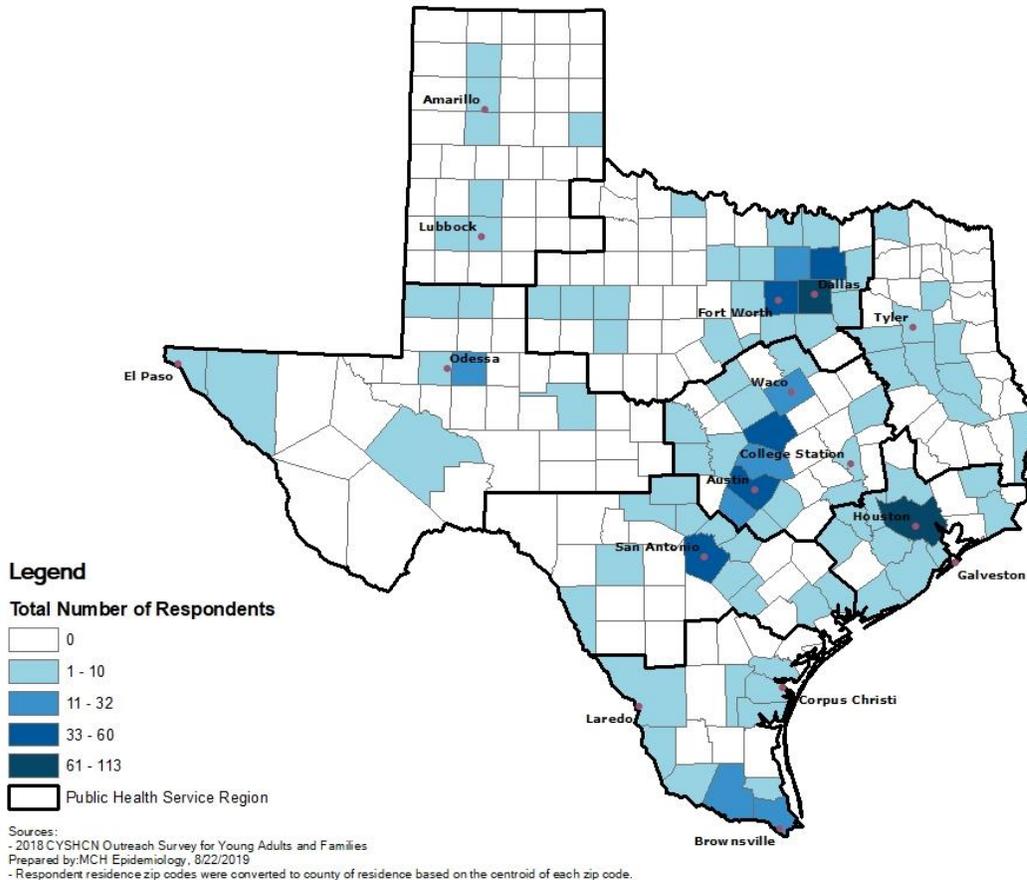
## Survey Findings

### Demographics of Respondents

There were 816 individuals from across the state of Texas who responded to the 2018 CYSCHN Outreach Survey. All eight public health regions are represented in the findings. Approximately 92% of the respondents were residents of urban counties while 8% were from rural counties. Additionally, 9.4% of the respondents live in border counties.



2018 CYSHCN Outreach Survey for Young Adults and Families Respondents by County



The respondents, as noted on Table 1, were predominately non-Hispanic White (50.4%) and Hispanic or Latino (39.0%). Most respondents were women (86.8%), took the survey in English (78.3%), and were a parent CYSHCN (88.9%). Eleven percent of respondents were young adults age 18 or older. The average age of respondents was 43.



**Table 1: Characteristics of the CYSHCN Outreach Survey Respondents**

Respondent Characteristics	Number of Respondents (n)	Average or Percent
<b>Average Age</b>	735	43
<b>Race and Ethnicity</b>		
<b>Non-Hispanic White</b>	372	50.4%
<b>Non-Hispanic Black or African American</b>	43	5.8%
<b>Hispanic or Latino</b>	288	39.0%
<b>Asian or Pacific Islander</b>	13	1.8%
<b>Other or Mixed Race</b>	22	3.0%
<b>Gender</b>		
<b>Man</b>	98	13.2%
<b>Woman</b>	643	86.8%
<b>Survey Language Taken</b>		
<b>English</b>	586	78.3%
<b>Spanish</b>	162	21.7%
<b>Respondent Was a Parent or Young Adult</b>		
<b>Young Adult</b>	81	11.1%
<b>Parent</b>	651	88.9%

Table 2 describes the characteristics of the CYSHCN whose parents took the survey. The children of survey respondents were approximately 13 years old on average. Racial and ethnic characteristics of the children were similar to those of the respondents, with children largely reported as non-Hispanic White (44.0%) and Hispanic or Latino (39.0%).

**Table 2: Characteristics of the CYSHCN**

CYSHCN Child Characteristics	Number of Children (n)	Average or Percent
<b>Average Age</b>	647	12.8
<b>Race and Ethnicity</b>		
<b>Non-Hispanic White</b>	342	44.0%
<b>Non-Hispanic Black or African American</b>	39	5.3%
<b>Hispanic or Latino</b>	289	39.0%
<b>Asian or Pacific Islander</b>	14	1.9%
<b>Other or Mixed Race</b>	57	7.7%
<b>Gender</b>		
<b>Woman</b>	300	40.4%
<b>Man</b>	443	59.6%



## Respite Care

Respite, a short break from the challenges and responsibilities of caregiving, offers parents the opportunity to take time for themselves to rest, refresh, and recharge. Only parents of CYSHCN completed this section of the outreach survey. According to the survey, 74% of parents reported needing respite to help care for their child. Additionally, 14.5% of parents responded that they need respite but have never received it.

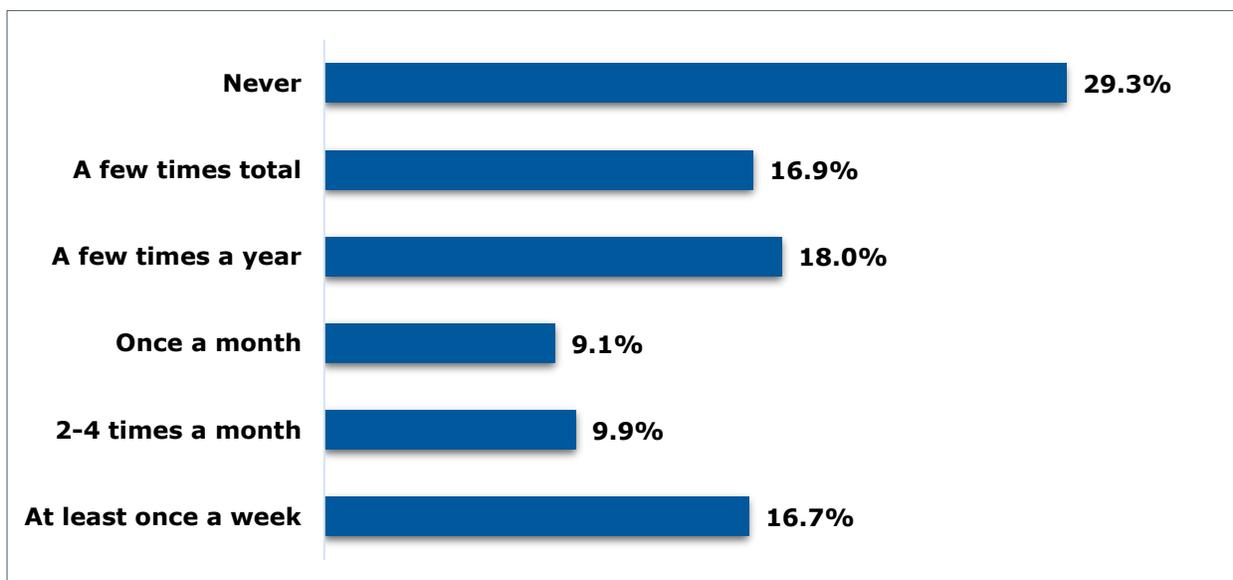
Respondents reported the following as the top three reasons for not using respite care.

1. I do not have the money to pay for respite (31.4%)
2. It is hard to find people who can provide respite for my child (29.1%)
3. I do not trust others to provide my child with the care that they need (22.7%).

Respondents also indicated that they do not use respite care because they did not know about it, they do not need respite care services, or there is not a respite care provider in their community. More financial assistance for respite care programs and increased outreach about existing programs can help reduce barriers to receiving respite care.

Figure 2 includes a breakdown of how often respondents indicated that they use respite care services. Approximately 29% of respondents indicated that they never use respite care services. About one in six respondents reported that they received respite care at least once a week (16.7%).

**Figure 2: Frequency that Respondents Were Provided Respite**

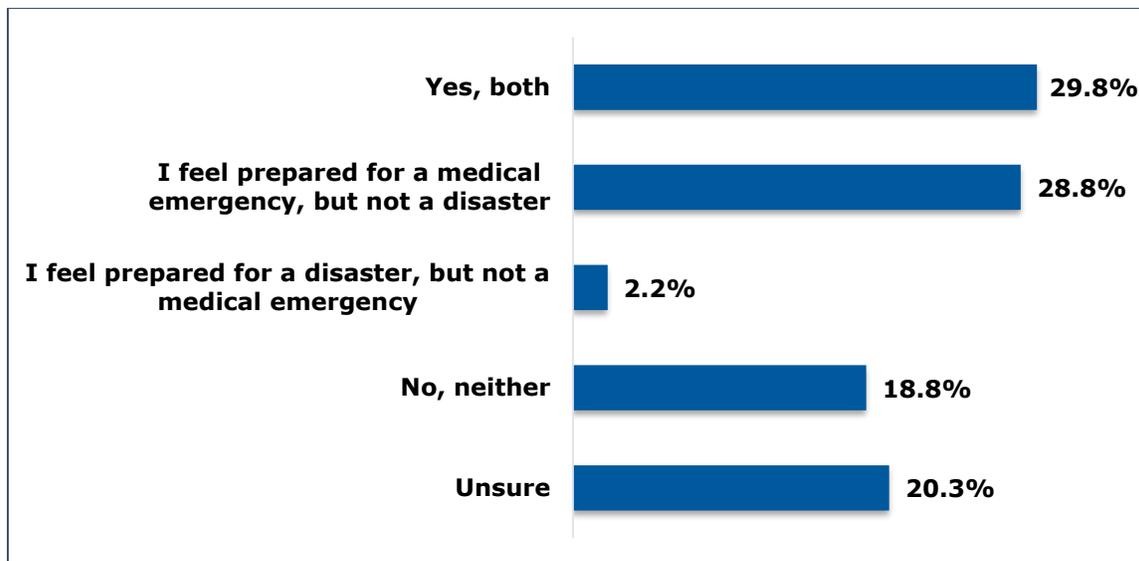




## Emergency Preparedness

In Texas, natural disasters can strike quickly and without warning. It is important for families of CYSHCN to be prepared for natural or manmade disasters, as well as medical emergencies. Families should have an emergency plan in place and know what kind of supplies, medications, and assistance they will need to be prepared for an emergency. According to survey responses, 29.8% of CYSHCN parents and young adults felt prepared for both a disaster and a medical emergency. Almost one in five respondents (18.5%) felt unprepared for either type of event.

**Figure 3: Do Respondents Feel Prepared for a Medical Emergency or Disaster (Natural or Manmade)?**



## Transition

Transition is the process of moving from childhood to adulthood. The transition process helps CYSHCN and their families prepare for adulthood in various areas of life. CYSHCN and their families work with health care providers to ensure that the youth can live as independently as possible. Although transition is different for each person, the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians recommend that transition planning begin by age 12. According to survey results, only 21% of respondents reported that they felt prepared for their or their child's transition to adulthood. Approximately 53% of respondents did not feel prepared, while 26% were unsure if they felt prepared for transition.

The survey asked respondents how they prepared for seven areas of transition. Table 3 lists the seven areas and describes how respondents prepared for each area of transition. Of the respondents that were prepared for transition, the majority prepared by themselves.



**Table 3: Who Helped in Preparing for Transition Needs**

Transition Need	Prepared by Themselves	Prepared with Parents/With Child	Prepared with a Professional	Have Not Prepared
<b>Medical Needs</b>	26.5%	15.3%	12.4%	45.7%
<b>Education Needs</b>	20.7%	15.5%	13.3%	50.4%
<b>Independent Living</b>	13.9%	9.7%	5.2%	71.3%
<b>Financial Needs</b>	13.9%	11.5%	13.1%	61.5%
<b>Social Needs</b>	21.3%	15.1%	5.1%	58.5%
<b>Employment</b>	13.8%	11.2%	10.4%	64.6%
<b>Legal Needs</b>	17.5%	10.5%	17.5%	54.4%

According to Figure 5, help and guidance from a person who is an expert in transition planning was the most reported (57.2%) thing to help respondents feel more prepared for transition. Financial assistance (41%), help and guidance from other young adults and/or parents of CYSHCN (38%), and a training session were among the most reported things that would help in transition.

The survey asked what would help them feel more prepared for transition to adulthood. The top three forms of support are listed below.

1. Help and guidance from a person who is an expert in transition planning
2. Financial assistance
3. Help and guidance from other young adults and/or parents of children with disabilities or special health care needs

### Care Coordination

Care coordination is one component of a medical home. If care is coordinated, then the child and his or her family work with multiple providers to develop a plan of care and ensure that the child can see a provider when necessary. According to the survey, 36.4% of respondents receive care coordination from a professional (e.g. someone at the doctor’s office, school, or a case manager or social worker). However, some respondents lack coordinated care and face many barriers in accessing care.

Respondents reported several barriers that keep them from accessing care for themselves or their child when sick. Specific barriers identified include:

- No medical provider in my/our community that is comfortable taking care of me/my child (20.5%)
- My/Our medical provider is far away (20.5%)

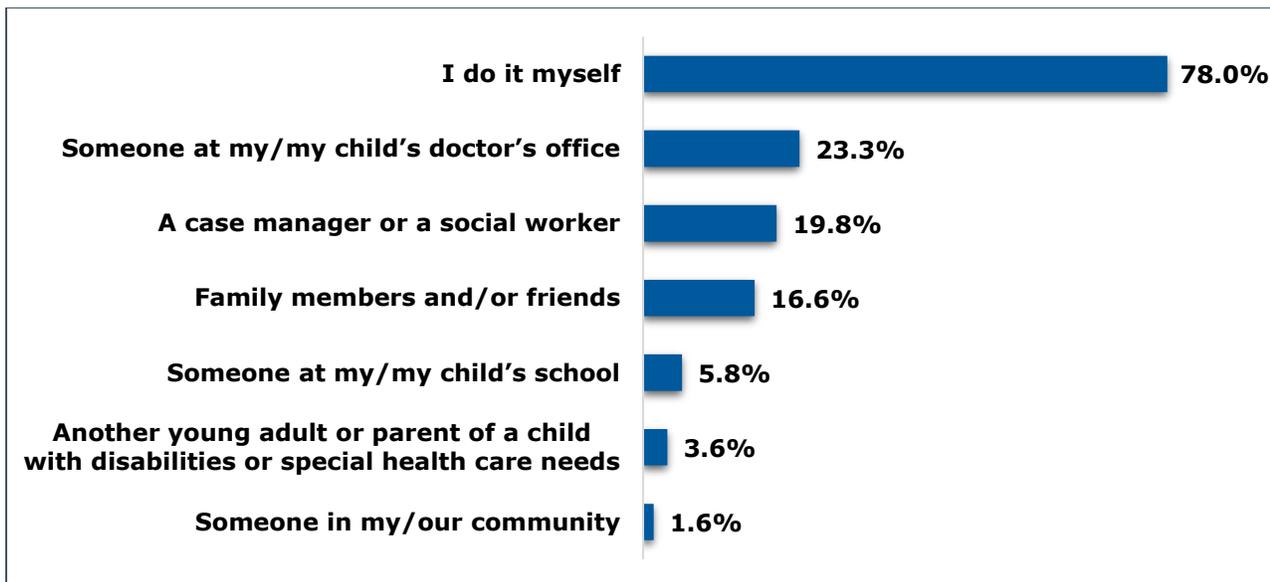


- I/we do not have money to pay for an office visit or co-pay (18.7%)
- There are no medical providers where we live (16.5%)
- We do not have health insurance (13.3%)
- There is little or no transportation to get to a medical provider (12.3%)

Nineteen percent of respondents indicated “Other”.

Respondents rely on different sources for care coordination. The chart below describes how respondents ensure that they or their child receives the care they need.

**Figure 4: Respondent Responses on Who Makes Sure That They or Their Child Receives All of the Care Needed (Respondents could choose multiple responses)**



### Community Inclusion

Community inclusion is the continuous support of CYSHCN and their families to be accepted in all parts of their community. It can be a challenge for families of CYSHCN to participate in community activities. Families encounter many barriers, such as lack of transportation, lack of adaptive equipment or technology, and financial barriers. An important part of community inclusion involves participating in activities with individuals without disabilities. Approximately 21% of respondents get this kind of interaction through social or recreational activities with friends in their community who have children without disabilities. Respondents also get this type of interaction through family members (15.4%) and faith-based organizations (13.0%).



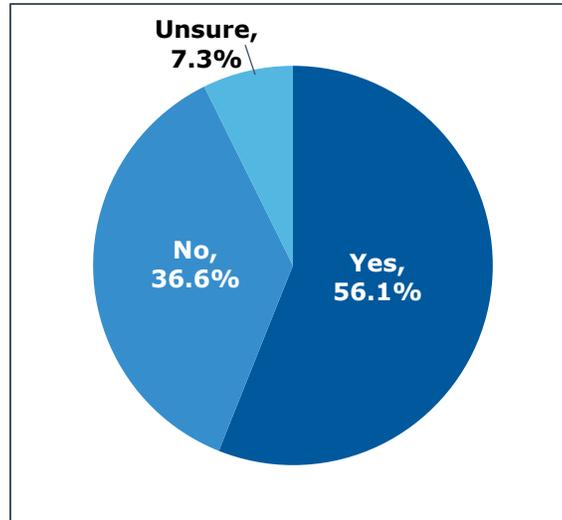
According to respondents, the most used supports or services in the community were family education (74.1%), social/recreational activities with families that have children without disabilities (72.8%), and assistance accessing medical supplies or medications (72.3%).

The three most needed supports for CYSHCN to participate in community activities were:

1. Establishments that are welcoming, inclusive, and accepting (41.8%)
2. Financial assistance (32.1%)
3. Behavioral supports (24.1%)

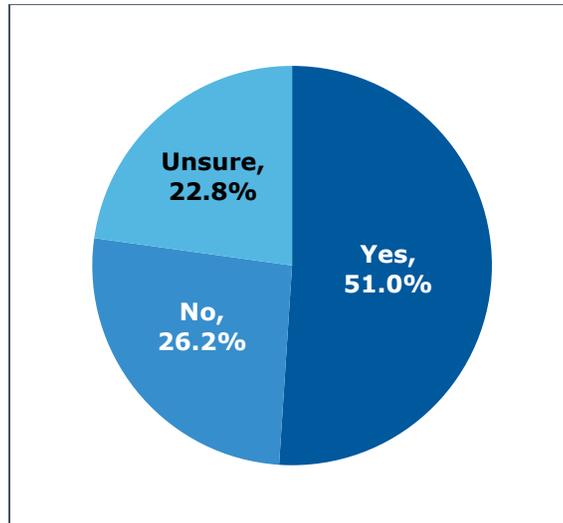
Families of CYSHCN often experience feelings of isolation from their communities. Figures 7 and 8, describe respondents' feelings of isolation and sense of belonging in their communities. These results correlate with the need identified for communities to be more welcoming, inclusive, and accepting to encourage families with CYSHCN to be more fully engaged. Compared to 2017 survey findings, the percent of respondents who reported feeling a sense of belonging has increased (40.3% to 51.0%), and the percent of respondents feeling isolated has decreased (61.3% to 56.1%).

**Figure 5: Respondents Reported Feeling Isolated Because of Disability**





**Figure 6: Respondents Reported a Sense of Belonging**



### **Limitations**

The 2018 CYSHCN Outreach Survey had several limitations. First, the survey was a convenience sample, which may not provide an accurate representation of the entire CYSHCN population in Texas. The CSHCN Systems Development Group will continue efforts to reach out to underrepresented communities and respondents through surveys and discussion groups. Additionally, despite increased outreach efforts to the predominantly Spanish-speaking community, fewer responses in Spanish were received in 2018 than in 2017. Future efforts will focus on improving outreach with targeted Spanish messaging.

Not all respondents chose to answer all survey questions. Consequently, each question detailed in this report has a specific number of associated responses.