

NEW HAMPSHIRE COUNCIL FOR YOUTHS WITH CHRONIC CONDITIONS 2022 FAMILIES NEEDS ASSESSMENT

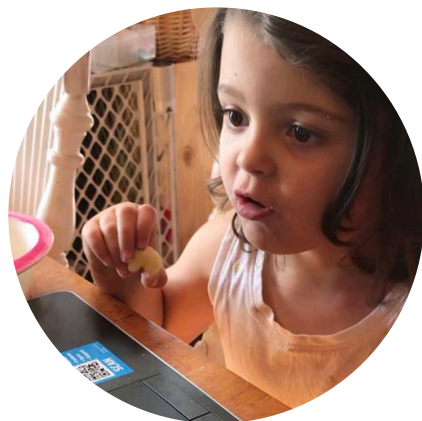


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SUBMITTED TO:

The New Hampshire Council for Youths
with Chronic Conditions

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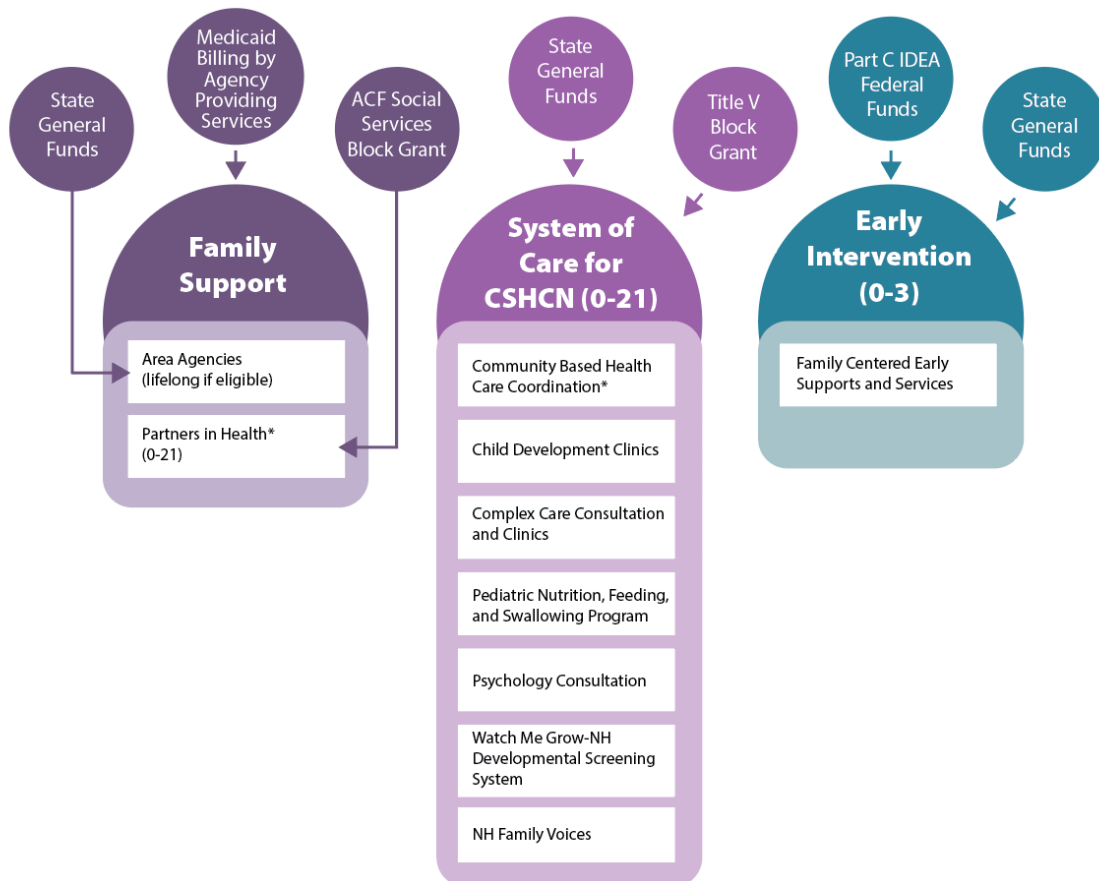
BACKGROUND

In November 2021, the New Hampshire (NH) Council for Youths with Chronic Conditions (CYCC) contracted with JSI Research & Training Institute/Community Health Institute (JSI/CHI) to conduct a qualitative needs assessment around families of children with a chronic physical health condition in NH. The focus of this needs assessment was on families with children with chronic physical health conditions who did not also have a developmental or intellectual disability and thereby were not connected to certain existing service systems, which put them at risk for having lower access and connection to critical supports.

JSI/CHI engaged an advisory group, composed of a subset of CYCC members, all of whom are parents of children with chronic conditions themselves, as well as state partners to provide feedback and assist with dissemination and recruitment for each information-gathering activity. In this report, JSI/CHI will present the findings from the needs assessment activities and offer recommendations to CYCC for future focus.

Together with the advisory group, JSI/CHI defined a chronic physical health condition as any ongoing illness or physical disability that lasts for longer than one year, affects the child's ability to function daily, and requires frequent and intensive medical care. Conditions such as allergies, asthma, AIDS, cancer, cystic fibrosis, diabetes, muscular dystrophy, and spina bifida fit this criteria. JSI/CHI then conducted a brief secondary data review of existing data sources to gather background information on the population.

Figure 1: NH Bureau for Family Centered Programs and Funding Sources



As shown in Figure 1, there are several state programs for which families with chronic physical health conditions may be eligible for, which are funded by a mix of state and federal funding. All fall under the purview of the Bureau for Family Centered Services within the NH Department of Health and Human Services (NH DHHS). Partners in Health is a community-based program offering services to families of children with chronic physical health conditions who do not have developmental disabilities. The System of Care for Children with Special Health Care Needs (CSHCN) (formerly known as Special Medical Services) oversees a variety of services families may be eligible for, including financial assistance, nutrition, feeding, and swallowing programs, and complex care clinics. Family Centered Early Supports and Services provides early intervention services up to age of three for certain physical health conditions as well as children with developmental delays or disabilities. The Maternal and Child Health Section under DHHS, which also receives Title V Block Grant funding, also offers programs families of children with chronic physical health conditions may engage with, such as the Newborn Screening Program. In addition to state programs, families of children with chronic physical health conditions may receive supports and services from condition specific organizations and other nonprofits.

While there are some data around the number of children and youth with special health care needs (CYSHCN), which includes but is not limited to this population, there are very little statewide data on the number of families with a child with a chronic physical health condition who does not also have an intellectual or developmental disability. Partners In Health had approximately 643 active cases as of September 2022. However, it is unclear how many families with a child or children with chronic physical health conditions are unaware of this program and therefore unenrolled. There are some data by condition available that may potentially shed light on the number of families impacted in NH. They include the following:

- From 2012 to 2018, approximately 130,969 children (ages 0 to 17) in NH had a diagnosis of asthma (NH Department of Health and Human Services [NH DHHS], 2022a).
- From 2015 to 2019, 303 cases of cancer (all types) were reported for NH children between ages 0 and 19 (NH DHHS, 2022b).
- From 2001 to 2016, the NH rate of type 1 diabetes for children (age 19 or younger) with private health insurance was 18.6 per 100,000. In 2016, it was estimated that 410 children (age 19 or younger) with private health insurance had type 1 diabetes (Rogers et al., 2018).

This needs assessment was not focused on quantifying the number of families in NH raising a child with a chronic physical health condition; instead, it attempted to understand the impact on the family as a whole and the daily challenges these families face. There is plenty of anecdotal knowledge among providers and families of these issues, and this needs assessment aims to help fill the gap left by the absence of any formal data available to quantify and qualify the unique experiences of these specific families.

METHODS

The needs assessment used a nonexperimental design and a mixed-methods approach. In order to produce meaningful findings, JSI/CHI conducted a six-part assessment in an iterative manner, with the results of each part informing the approach and focus of each activity that followed:

- Secondary data review
- Listening session
- Community survey
- Photovoice
- Key informant interviews
- Focus groups

JSI/CHI met monthly with the advisory group throughout the length of the project to gather input on each of these activities. The advisory group also played a key role in engaging other organizations and recruiting families. JSI/CHI obtained through its institutional review board (reference number 22-05E) approval for each activity to ensure that participants' rights and confidentiality were protected. All participants, with the exception of those who attended the preliminary listening session and key informant interviews, received a gift card to a business of their choice for participating. Informed consent was provided to all participants and included an explanation on how data would be used and protected as well as potential risks and benefits to the participant. Verbal consent was obtained for key informant interviews and focus group participants older than age 18. Written consent, including caregiver consent, was obtained for all Photovoice participants and focus group participants younger than age 18.





Secondary Data Review

As mentioned in the background, there are a lack of quantitative data at both the state and national levels on this specific population. JSI/CHI reviewed publicly available data sources of condition-specific data and CYSHCN data, including from the Centers for Disease Control and Prevention, the American Community Survey, and the NH Department of Health and Human Services. However, after receiving input from the advisory group, it was determined that these data were insufficient to provide direction for the needs assessment. It was decided that direct feedback from caregivers through a listening session would better offer areas of focus.

Listening Session

JSI/CHI convened a preliminary virtual one-hour listening session to hear directly from caregivers the kinds of questions they would like to be asked through the needs assessment activities. JSI/CHI posed high-level questions to create conversation space for caregivers to reflect on the following line of inquiry: What are the most important aspects of your experience as a caregiver/family member of a child with a chronic condition that should be included in the needs assessment data collection tools? Seven caregivers attended and shared their experiences. Based on the information gathered and with input from the advisory group, the following research objectives were created:

Research Objectives

-  Contextualize the financial impacts families face in caring for a child with a chronic condition.
-  Understand the holistic impact managing a youth's chronic condition can have on a family.
-  Describe both the supportive and challenging features of the current continuum of care (community-based, clinical, etc.) to support children with chronic conditions, their caregivers, and their families. Describe strengths and challenges in accessing a comprehensive range of services to support families managing a youth's chronic condition.
-  Identify communities with greater need and the unique challenges they face.

The methods for each subsequent activity are outlined below, and their results are interwoven throughout the rest of this report.

Inclusion Criteria

With the exception of the key informant interviews, which focused on service providers, the main population recruited was caregivers older than age 18 with a child ages birth to 21 or a young adult ages 18 to 21 with chronic physical health conditions. The following activities had additional eligibility:

- Photovoice: children younger than age 18
- Focus groups: adolescents ages 15 to 18

Families receiving agency area services were excluded, since families with children with only chronic physical health conditions are not eligible for these services. However, given the overlap in spaces where these families interact and receive services, some families who receive agency area services inadvertently participated in some of the qualitative needs assessment activities. Data received from participants about the services they receive through agency area services were excluded from the final analysis.

Survey

Two statewide online surveys were conducted electronically from February through March 2022. The caregiver survey generally aimed to identify caregivers' experiences in accessing necessary resources to support their family as they care for a child with a chronic physical health condition. The young adult survey similarly aimed to identify the experiences of young adults in accessing necessary resources to support their chronic physical health condition. The anonymous surveys employed a structured written questionnaire and were based on nonrandom sampling targeted at adults who met the inclusion criteria above. The survey was translated into five languages: French, Spanish, Chinese (Simplified), Nepali, and Vietnamese. In total, 67 respondents completed the survey.

Photovoice

In May and June 2022, JSI/CHI engaged eight families in a storytelling project called Coming Into Focus. This portion of the needs assessment used the participatory action research method Photovoice. Photovoice uses visual data to center lived experience in research findings and engages community members as co-researchers. Given how the framework incorporates independent and group work and uses multiple means for contributions, it is considered a highly accessible and inclusive research method, and research has shown it to be a promising tool in disability advocacy. For this needs assessment, Photovoice was utilized as a means to provide a first-person view into parts of the families' experiences that could be captured in a photo—for example, families experiencing joyful moments, the ways in which the presence or absence of home modifications affects the family, and the ways in which their neighborhood and community are or are not accessible.

JSI/CHI recruited co-researchers through CYCC partner networks and from the pool of survey respondents. Families and children interested in participating were provided a detailed overview of the project and asked to complete a brief screening questionnaire so that the project team could confirm eligibility. Families self-selected their participation in one of two project cohorts, based on their availability for an orientation session.

During the orientation sessions, JSI/CHI provided an overview of the ethical and safety considerations for this type of data collection, described the specific research questions for this project, and detailed the process by which families could approach the work. Co-researchers were given three weeks to take photographs representing the answers to the project's research questions and submit a brief log describing the photograph. Co-researchers primarily submitted photos and PDF logs via email and, in some instances, used text messages to submit their contributions. In those cases, JSI/CHI transferred the text message content into a PDF log and confirmed that all the necessary information was included. During the closeout sessions, co-researchers each presented three of their favorite photos. JSI/CHI facilitated an exchange of reflections and conversation among participants, which further elicited meaning for each photograph. Resulting from Coming Into Focus, JSI/CHI incorporated 62 photographs and 59 logs into its qualitative data set.

The project culminated in the Coming Into Focus community gallery walk, which was hosted as part of the 2022 CYCC Annual Family Event. Completely voluntary, co-researchers were invited to select a set of their photographs that would be printed in a large format and displayed for the event's duration. JSI/CHI used the logs submitted with each photograph as captions for the photographs, each of which was reviewed and approved by the contributing family. The final gallery portfolio included 25 pieces of art selected from the full 62-item visual dataset.

Key Informant Interviews

JSI/CHI conducted nine interviews through June and July 2022 via Zoom with 20 providers and other key partners who serve and/or advocate for children and/or young adults with chronic physical health conditions in NH. These interviews aimed to understand from the providers' and organizations' perspective the strengths and challenges facing young adults and families of children with chronic physical health conditions, what the current system of support and services in NH for this population is doing well and how it is failing to meet the needs of this population, and what providers and the current system need to better serve these families.

Focus Groups

JSI/CHI conducted 10 focus groups with 40 participants either virtually through Zoom or in person in August and September 2022. An 11-question interview guide was developed that focused primarily on the holistic impact of chronic physical conditions. Focus groups generally lasted for one hour, with the exception of a focus group conducted at a summer camp for families of children with cancer. In that case, caregivers were interviewed one on one using an abbreviated version of the focus group interview guide.

Data Analysis

Qualitative Analysis

Qualitative analysis took a systematic and iterative approach. All Photovoice, key informant interview, and focus group transcripts and field notes were analyzed using Dedoose, a qualitative analysis software program. Prior to the start of qualitative coding, the JSI/CHI team met to review the data, discuss the codes to be used, and develop a coding plan. Coding categories were derived from the data as thematic coding progressed. Two data analysts coded the text data, meeting regularly to identify and discuss patterns and themes emerging from qualitative answers. Thus, findings evolved over time through a process of identification, review, and confirmation or refutation.

Quantitative Analysis

Quantitative data analysis focused primarily on survey data. Data analysts explored and cleaned all quantitative data to check for incomplete or fraudulent responses and create any needed variables for the analysis. Descriptive statistics, including frequencies, were calculated. Data showing very small numbers (i.e., with a numerator <5 or a denominator <15) are suppressed in this report to protect against indirect identification of individuals and reliability of estimates.

Limitations

Two data-related limitations hindered the methods and resulting findings for this needs assessment:

1. Absence of administrative quantitative data reflecting the complex experiences of families managing a chronic disease diagnosis for their child
2. Inadequate representation of communities experiencing greater inequities

Given the unknown quantity of families of a child with a chronic physical health condition in NH, it is impossible to determine whether the total number of participants recruited sufficiently represents the population as a whole. In addition, eligibility criteria and recruitment methods provided a survey sample that represents a select group of NH residents. These findings, therefore, should not be generalized to the entire population of NH.

JSI/CHI is committed to continual learning and exploring culturally humble and community-specific engagement approaches to help fulfill its commitment to addressing health inequities. At each phase of the project, JSI/CHI reflected on the effectiveness of each engagement and recruitment strategy. Those considerations led to shifts in how the project team approached engaging its audience, including attending community meetings, shortening the time commitment for families to share their stories, and speaking with respected leaders representing underresourced communities to understand barriers to engagement.

Despite these attempts to adapt recruitment strategies within the project period and allocated resources, JSI/CHI was not successful in adequately engaging Black and Indigenous people of color (BIPOC), immigrant/refugee, and non-English-speaking communities in the state. Therefore, findings around the challenges these communities face are based on provider input and other health-related needs assessments conducted in NH. This result, while disappointing, has led to the following insights for consideration in future data collection activities:

- Needs assessment fatigue—defined as a sense from participants that they continue to offer feedback but do not see change—is a very strong deterrent to participation.
- Personal connections to communities is critical. It is important to engage local community leaders and build trust with them. The time it takes to build these relationships often spans beyond a single project.
- Recruitment methods must adapt to every community and may require adaptations of traditional data collection activities to meet participants where they currently are.

Demographics

Survey

Sixty-seven respondents completed the online survey. The majority (88%) were a caregiver (age 18 or older) of a youth younger than age 21 with chronic physical health condition(s), and several respondents (12%) were young adults (ages 18 to 21) with a chronic physical health condition(s) living either independently or with their family.

Caregivers

Of the caregivers who completed the survey, the majority identified as women (95%), identified as straight or heterosexual (84%), were White (97%), were ages 35 to 54 (77%), and were the biological parent of a child or children with chronic physical condition(s) (93%). Half of respondents had an annual family income of less than \$59,999. Respondents lived in nine NH counties (36 unique towns), with the most having a town of residence in Hillsborough (33%), Merrimack (14%), and Strafford (12%) counties.

Seventy-eight percent of respondents reported having one child with a chronic physical health condition(s) living in the household, followed by 20% who had two children meeting this criteria. The average age of their children with a chronic physical health condition(s) was 11 (with the maximum age 19 and the minimum age younger than 1), and the majority were White (84%). Respondents reported that their child or children had a wide range of chronic physical health conditions, with many indicating that their child or children had multiple diagnoses. The most frequent types of chronic health conditions reported were asthma, autoimmune conditions, diabetes, neuromotor conditions, epilepsy, congenital heart conditions, and cancer.

Young Adults

Young adult survey respondents (eight) were between ages of 18 and 20, were women (80%), were White (60%) or Black/African American (40%), identified as straight or heterosexual (60%) or bisexual (40%), and received less than \$15,000 per year from all sources (80%). Respondents' towns of residence were in Hillsborough, Belknap, and Cheshire counties. Similarly, young adult respondents often reported that they had multiple chronic physical health conditions, including asthma, epilepsy, blood-related conditions, congenital heart conditions, autoimmune conditions, and cystic fibrosis.

Key Informant Interviews

A total of 20 key informants were interviewed. These informants all serve and/or advocate for NH children and/or young adults with chronic physical health conditions. They represent a range of professions working in a variety of settings, including pediatricians, pediatric specialists, care coordinators, representatives of state agencies, disability rights advocates, nonprofits, and resettlement agencies.

Photovoice

Eight families participated in the Photovoice project. The majority of these participants were mothers of a child or children with a chronic physical health condition(s). Additionally, children were invited to participate, and three of them joined the project (e.g., took photos, attended the project orientation and/or closeout session). The families who participated had a child or children with a chronic physical health condition(s) ranging in age from 1 to 10, and the majority lived in southern and western NH. Examples of chronic health conditions represented were diabetes, seizure disorders, connective tissue disorders, cerebral palsy, asthma, and gastrointestinal/digestive disorders.

Focus Groups

Of the focus group participants (40), the vast majority were a parent or caregiver of a child or children with a chronic physical health condition(s). A small number were teens (ages 15 to 18) or young adults (ages 18 to 21) who have a chronic physical health condition(s). They reported living in Hillsborough, Cheshire, Strafford, Merrimack, Rockingham, and Grafton counties. Of the parents or caregivers, most were mothers, followed by a few participants who indicated they were fathers or stepfathers. The average age of their child or children with a chronic condition(s) was 14 (with the maximum age 19 and the minimum age 2), and they had a wide variety of chronic physical health conditions, including cancer, muscular dystrophy, diabetes, epilepsy, asthma, autoimmune conditions, blood-related conditions, and cystic fibrosis.

Key Findings

Key findings of this needs assessment are organized around each research objective, but JSI/CHI encourages readers to consider how many of the findings cut across all four objectives. Supporting evidence was pulled from the survey, the Coming Into Focus Photovoice, key informant interviews, and focus groups. Please see the appendices for full survey results and coding schema for the key informant interview, Coming Into Focus, and focus group activities. Throughout this report, you will see photos from the Photovoice project; to view the full gallery, visit the Coming Into Focus gallery walk page of the NH CYCC website.

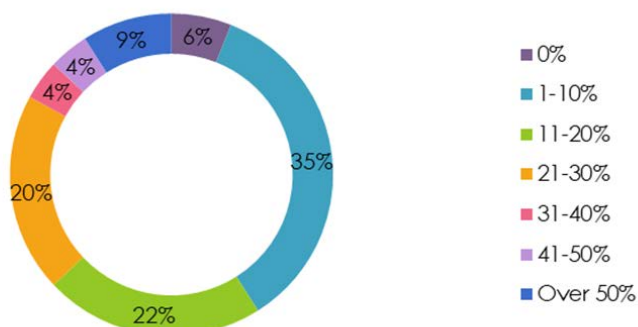
Research Objective 1: Contextualize the financial impacts families face in caring for a child with a chronic condition.

It's a lot, the financial impact is enormous, and it comes up for everything. You have to do all sorts of testing, MRIs and all of that other stuff. None of it's cheap, ever. And anything special that comes up, anything out of the ordinary, we're just going to max out. Everything's going to get maxed out. And then you may not even be done paying the bills from the previous year and you start on the next year. —focus group participant

Key Finding 1.1: Families shoulder a high percentage of the medical costs associated with the chronic condition.

The community survey found that while 35% of respondents reported spending 1%–10% of their monthly household income in covering the cost of managing their child(ren) with a chronic physical health condition(s), 20% reported spending 21%–30%, and 9% reported spending more than 50% of their household income.

Figure 2. Average Monthly Percentage of Household Income Spent Covering the Cost of Managing Child's/Children's Chronic Physical Health Condition(s) (n=54)



This was echoed in key informant interviews with providers, who reported that while most families have insurance coverage, it is often insufficient and carries high out-of-pocket costs. Thirty percent of survey respondents reported finding that their insurance coverage did not adequately cover services needs or offer needed benefits. They cited high deductibles and coinsurance and a lack of coverage for over-the-counter medications, alternative therapies, and specialized medical equipment. In addition, the most common barrier respondents identified to getting the services and supports their families need was high out-of-pocket costs (32%, n=47).



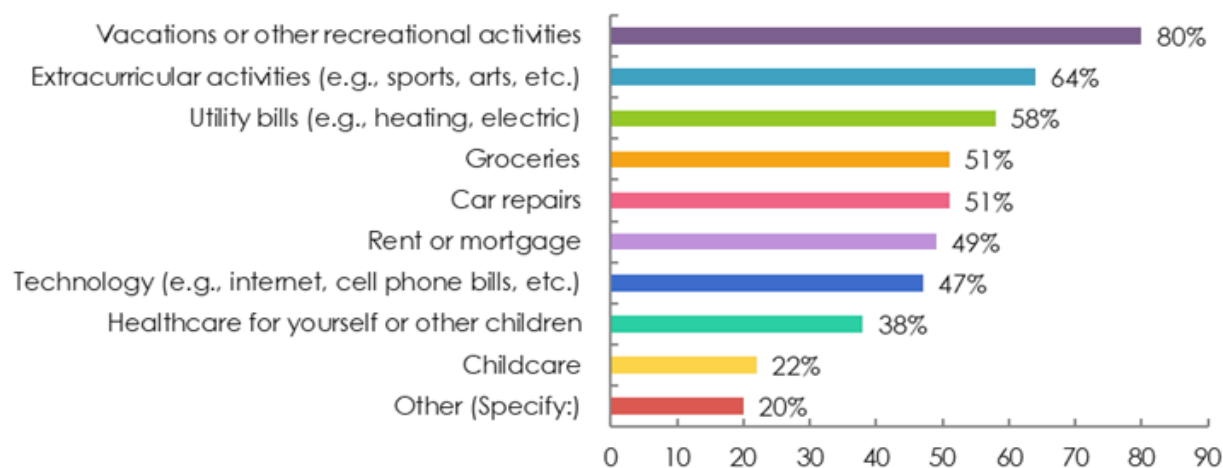
"Medication and medical costs are the biggest stress in our lives right now. No family should have to choose between feeding themselves or their life-saving medications."

Multiple Coming Into Focus co-researchers reflected specifically about travel-related out-of-pocket costs. Many families travel to Boston, Maine, or other areas for specialty care. As a result, families are not only missing employment-based earning opportunities, but they are also dealing with additional fuel costs, expensive parking fees in urban areas, and other incidental costs, such as for food and water.

The financial toll of caring for a child with a chronic health condition was expressed in every focus group and was one of the most frequently discussed themes. Families described paying high monthly rates for medical insurance, experiencing issues with insufficient insurance coverage, and paying high out-of-pocket costs for co-pays, ambulance trips, prescription medications, and travel associated with medical care (e.g., parking, food, flights, and lodging). Travel costs were highlighted frequently due to families' need to travel long distances within state and often out of state for specialty care. Sixty-nine percent of survey respondents shared that the average distance from their home to a needed service or appointment was greater than 40 miles. The majority of focus group participants have had to travel to Boston or to Dartmouth Medical Center in Lebanon, NH, to obtain the medical care their child needs. In addition, a few focus group participants have had to travel to other regions of the United States for specialty care or to participate in experimental treatments.

Key Finding 1.2: Some families are unable to afford essential needs of daily living.

Figure 3. Items/Services Families Have (at Times) Had a Hard Time Paying for or Had Not Been Able to Pay for at All due to Costs Involved in Caring for a Child or Children) With a Chronic Physical Health Condition(s) (n=45)



Some families struggle to cover the costs of essentials such as housing, food, and utilities. More than half of survey respondents reported having a hard time covering utility bills, groceries, or car repairs. Forty-nine percent reported having a hard time paying for their rent or mortgage. Struggling to make ends meet was also a key theme in focus groups. Many participants shared concerns with being able to afford living costs and having to seek out services such as the Supplemental Nutrition Assistance Program (SNAP), food banks, and heating assistance in the winter. A theme that arose was needing to adjust to living simply by prioritizing essential costs and putting off nonessentials. For some, this included foregoing long-term investments such as retirement and saving accounts. One participant illustrated this: “It’s constantly worrying about bills. I’ve learned to live on very little money. And I’ve taught my kids also that you have to think about life as not always wanting things.”

As one provider explained in a key informant interview, “Keeping the electricity on, keeping heat in the house. Those are medical needs. You can’t keep an ill child in a cold home, but nobody wants to assist in paying for those things. And there are families that don’t qualify for any of these programs that are out there, fuel assistance, and all that . . . Get into a pickle once in a while, and the car breaks down. And there’s nothing, nothing. There’s some grants out there, but grants, you’ll get paid in three months. And what do you do today?”

Another essential need families struggle to cover are needed home modifications so that their child can comfortably live in their home. Ninety-one percent of those that made home modifications covered the costs themselves. Notably, 14% relied on crowdsource funding. In the focus groups, participants described issues with accessibility in their homes that they had foregone renovating due to the cost. For example, one participant stated, “Then just trying to figure out how to make things accessible to him at the house for right after his amputation . . .



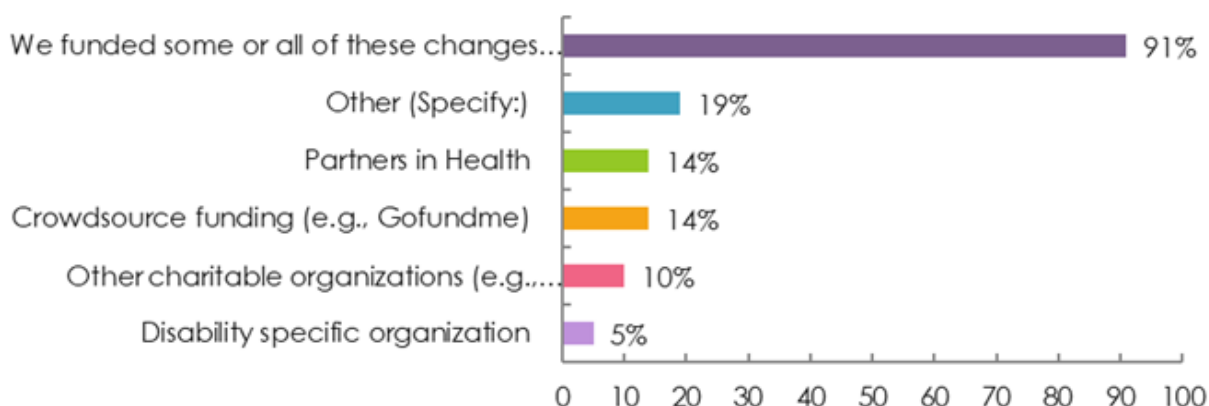
"The toilet is too tall, so he has a stool to sit on. My child vomits and has diarrhea a lot, which makes for a lot of washing. I don't have good access to a washer and dryer. This is three days' worth of clothes on hanging on the rack, looking like an audience waiting to see what happens."

Thankfully he took to the walker, and he was kind of able to make it work . . . because we've got a lot of stairs, and it is not handicap-accessible, and we didn't have the money to even get a temporary ramp."

One Coming Into Focus co-researcher reflected on the dual challenge of not having appropriate home modifications, which resulted in greater ongoing costs to the family. Due to the child's chronic condition affecting his digestive system, the family is burdened with additional laundry tasks. The family doesn't have a washer and dryer in their home and has to use older, inefficient washer and dryers in their apartment building, which require additional cycles to fully clean and dry the clothing.

Figure 4. Home Physical or Structural Change Funding Source(s) (n=21)

Note: Totals exceed 100% because this survey item allowed for respondents to select multiple response options.



Examples of the most common needed home modifications that respondents reported included electrical work, wider doorways, and accessible showers. In focus groups, families who live in apartments reported being unable to make needed modifications or wanting to move but being unable to find other suitable housing.

Key Finding 1.3: Family budgets are often unable to absorb the costs of vacations and extracurricular activities.

As seen in Figure 3 above, the top two costs families are unable to afford are vacations (80%) and extracurricular activities (64%). These were also frequently cited in focus groups. Participants described the cost of medical care and living as being essential, forcing them to forego nonessentials such as recreation and other family activities. A focus group participant spoke to this topic, stating, “We haven’t been on vacation, other families get to go away on vacation and it’s just not something we have a budget for. But that kind of thing would bring us joy.” Another described, “I lost all income We really relied on my husband’s income It wasn’t super tight, thankfully, I mean, because insurance did pick up a lot of the bills that we were really worried about, but it still hurt. Because my income was more things for him, like sports and the nonessential stuff. But to a 9-year-old, they are essential.”

Participants described how these decisions to cut back on extracurricular or recreational spending could be a cause of conflict for the family as their children did not always understand the financial decision making involved.

In addition to cost, families also face logistical barriers to spending time doing activities outside of the home. Coming Into Focus co-researchers and key informant interviews both reflected upon the lack of affordable or free summer camps for children with chronic health conditions and other recreational activities. Families are challenged in finding places that can accommodate their needs and also having to make contingency plans in the event an itinerary needs to change quickly.

“Here we are, waiting in the car. We try to extend our time as a family by bringing a wheelchair and going places that are wheelchair-accessible and sensory-friendly. Sometimes that’s not possible, so I make sure to have a plan B and try to park our vehicle as close as possible for quick exits.”





"I have to be carried into a lot of houses. I like this friend's house because it's fully accessible. I can go everywhere—even roll into the shower! It's awesome, and I feel included."

Key Finding 1.4: Caregiver employment is often affected by the demands of the chronic condition.

Table 1. Impacts on Survey Respondents' Job Status (n=54)

	Temporary	Permanent	I have not had to do any of these
Take leave without pay	20	8	26
Change from full-time to part-time	13	14	25
Stop working	21	14	19
Change the days or time of day you work	16	14	23
Total count	70	50	93
% of total	33%	23%	44%

Note: Total counts exceed the n (54) because this survey item allowed for respondents to select multiple response options.

Caring for a child with a chronic condition often creates challenges in keeping steady full-time employment. In the caregiver survey, more than half of respondents had to make either temporary or permanent changes to their employment. This included taking leave without pay, reducing hours, changing schedules, and leaving the workforce completely. Similarly in focus groups, families with two caregivers mentioned one caregiver deciding to stay home to manage appointments and treatments and the other caregiver working full-time or even more to financially support the family. One focus group participant shared, "Even though I have a college degree in education and stuff, my husband's job paid more. So he worked during the day and I had to find jobs that weren't per se what I envisioned doing because they were available in the evening So even though it wasn't what I had my degree in, it was what I had to do to pay the bills."

Sixty-four percent of survey respondents mentioned that the changes they made in their employment resulted in changes in their employment benefits such as health insurance, dental insurance, and paid time off. One young adult participant also shared challenges in finding employment: “It’s already impacted my finances, too, even though I’m not paying for any of my health stuff just because I can’t work jobs where I have to stand up for a long time, more than an hour, which, when you’re a teenager, that’s a lot of the options you have is retail or at the grocery store or whatever.”

Key informant participants also observed the tension between employment and managing a child’s chronic condition, citing caregivers having difficulty getting time off of work to make appointments and caregivers expressing fears of losing their job due to taking too much time off to care for their child.

Research Objective 2: Understand the holistic impact managing a youth’s chronic condition can have on a family.

The aftermath [of cancer treatment] and the post-traumatic stress every family goes through If you don’t realize it, it’s there, but you have this level of trying to figure out what’s your new normal. A family was asking my partner yesterday, ‘How long did it take you before you weren’t panicking all the time?’ And we’re sort of like, ‘Who says we don’t?’ You learn to live with it, but . . . you’re always worried it’s going to come back.

—focus group participant

“In this picture, I am mentally exhausted. This is the reality of caring for a child in a pandemic. My daughter had been to the emergency department because she was very ill but [was] sent home because there were no hospital beds. Parents are trained to provide a high level of medical care at home, and it puts a huge strain on the family.”



Key Finding 2.1: Families of children with chronic physical health conditions are incredibly resilient, but the chronic stress of caregiving affects both the emotional and physical health of parents/caregivers.

Throughout every key informant interview, providers mentioned the strength and resilience of these families. One participant stated, “Part of the resiliency is to say, ‘Well, look. You told me no. Let me go here. You told me no, let me see if there’s somebody else who’s willing to help. Let me think outside of the box to be able to try to solve this problem for my child.’ I regularly see that with parents who are willing to do that and kids too.” However, that persistence can often take a toll, as another provider explained: “Families will go to the ends of the earth to try to find what they need for their kids and put themselves into extreme financial hardship to get what they need for their kids as well as really physical hardship because oftentimes they’re not getting enough sleep or self-care because the kids are first.” This sentiment was universally shared by each Coming Into Focus co-researcher and reflected in many of the submitted photos.

Figure 5. Caregivers/Parents Ratings of Their General Physical Health Status (n=53)



Figure 6. Caregivers/Parents Ratings of Their Mental and Emotional Health Status (n=53)



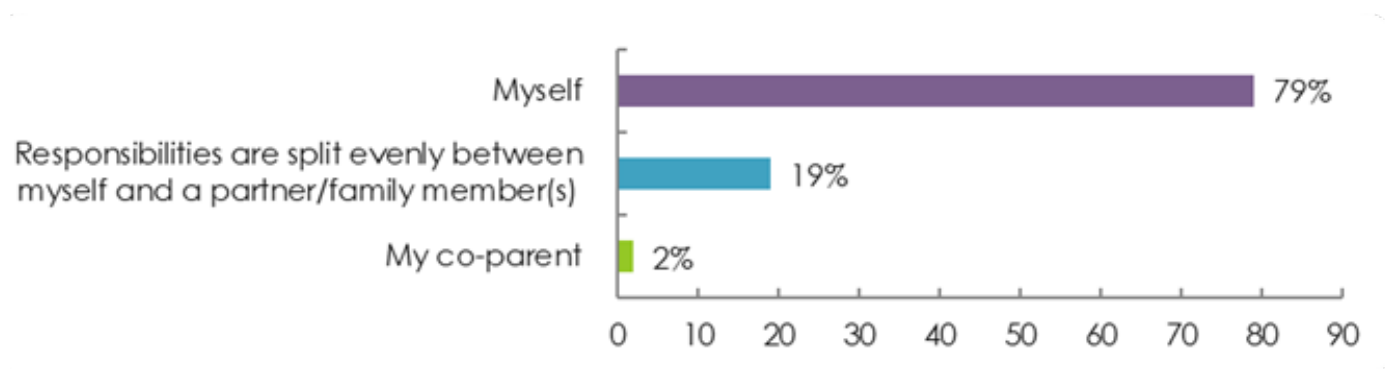
Other needs assessment activities echoed these health effects. Almost half of survey respondents rated their physical health and/or their emotional health status as fair and poor. Caregivers in focus groups who have a chronic condition themselves shared how challenging it is to manage both their own condition and care for their child. Throughout the focus groups, participants frequently cited challenges with their emotional and mental health. As one participant put it: “You have to keep it together with your marriage, and with your other kids, and healthy relationships. Then you just go cry in the tub because you don’t want your kids seeing mom not being strong.” Providers also shared that they frequently see caregivers show signs of mental health distress and are in need of support.

Fathers who participated in a focus group noted that they had observed or experienced unique emotional or psychological challenges due to cultural tendencies of men to be more reserved and less expressive of their feelings. Due to this, they reflected that this population was less likely to seek out social support from peers or formal mental health services. One father shared, “I think as a dad, I’m a different type of person, so I can be open and candid with people just because of those life events I’ve been through. But to see others that are very reserved, they don’t even have any place to go to listen. And I think there’s dads out there that are being missed, and they need support, but they don’t know where to go, or they’re very reserved.”

Key Finding 2.2 Caregiving falls on the family, at times unequally, and can affect the relationship between caregiver partners.

As mentioned previously, the majority of survey respondents identified as women. These survey respondents also overwhelmingly responded that they take on most of the responsibilities related to their child or children) with a chronic physical health condition.

Figure 7. Who takes on most of the responsibilities related to the care of your child(ren) with a chronic physical health condition(s)? (n=53)



JSI/CHI dug deeper into this topic in the focus groups. Regardless of gender, many participants shared that mothers tended to take a larger role in caregiving. Often this is due to decisions made around employment, in which one caregiver continues to work to financially support the family and the other caregiver leaves the workforce to coordinate appointments, treatments, and care for the child with the chronic physical health condition as well as care for other children in the family. As another focus group participant who identified as a mother explained, “He’s [the father] never home. I’m a single mother, basically, because he works so much. He has a

second job, too . . . and he feels that burden because he's the only one working right now." Several caregivers mentioned periods of time, especially during hospitalizations, when they did not see their partner for days or weeks at a time because their partner had to continue to work for financial reasons.

Caregivers who identified as mothers who participated in the focus group described assuming roles that were often that of a direct care provider to their child with a chronic health condition and included managing their daily care such as in-home treatments (e.g., injections, medications) and assisting with or performing activities of daily living (e.g., feeding). As one father participant explained, "My wife has become her own self-taught medical expert." Another focus group participant reflected, "I think early on I felt more like a nurse. A lot of the stuff we did together was treatments and therapy and that kind of thing. It's only been very recently—and I'm talking since he was in high school—that I stopped and just relaxed a little bit more and tried to do more, just be a mom and a son." These caregivers also took on roles in the coordination of their child's care and often education as well. They described being the appointment scheduler, coordinating services, planning and providing transportation to appointments, staying with their child through hospital stays, and communicating with insurance companies.

The stress of caring for a child with a chronic condition can affect relationships between caregiver partners both positively and negatively. Focus group participants often reflected on the lack of quality time as having a negative effect on their relationship. One focus group participant shared, "Looking at it now, we were just kind of roommates just kind of going through, and it wasn't until [their child] finished treatment that we kind of realized that. So, it's like I can understand why so many couples end up getting divorced during a time like this or afterwards because now we're trying to figure out a new normal." Other focus group participants cited feelings of resentment and stress at being the primary caregiver, while others shared that the challenge strengthened their relationships.



"We keep our community small. It is too overwhelming to be in public long, especially given the lack of public bathrooms. Our greatest community is that of our family. In this photo, my son has found a friend within the backyard oasis of his grandparent's home."

Key Finding 2.3: Families often feel isolated from social circles and personal supports.

It was clear throughout the needs assessment that families often feel alone and isolated in their daily lives. Thirty-four percent of survey respondents did not have someone to turn to for day-to-day emotional support with parenting or caregiving. Coming Into Focus photographs, logs, and group discussions also reflected this theme of isolation and how important it was to be creative in creating spaces for connecting.

“These are our animals. They help our kids when they are having a difficult day. Animals not only bring joy, but can also help with anxiety and bring a calmness to an environment.”



The sometimes grueling schedule of appointments and treatments and separation from partners because of work takes a toll on caregivers. One focus group participant shared, “I started seeing a therapist, too, because you just hurt, carry this huge burden of guilt. You take it for granted until you don’t have coworkers to talk to about things. But basically, I’ve had my kids, and I don’t really have too many close friends. So you just carry this huge burden.” Another participant shared, “The last time I hung out with a friend, kid-free, was my high school reunion in 2018 . . . I’m running on an hour-and-a-half of sleep and no reprieve, no other adult to talk to. It gets to be so much.”

Alternatively, families that have been able to connect with other families with similar conditions shared how helpful it was to have other people to talk to with similar experiences and as an opportunity for information sharing. One caregiver who joined a support group for childhood diabetes shared, “We learned so much from that. The parents went in one room, and the kids went with a child specialist to play games. And that was really helpful.” The same caregiver went on to explain, “Just parents in general, we know each other, we share supplies. If I have too much, like I have a lot of pods for the insulin pump, so one of the friends will call, and she’ll say, ‘Oh, do you have any extra pods?’ I say, ‘Sure, coming over.’ And she takes pods.”

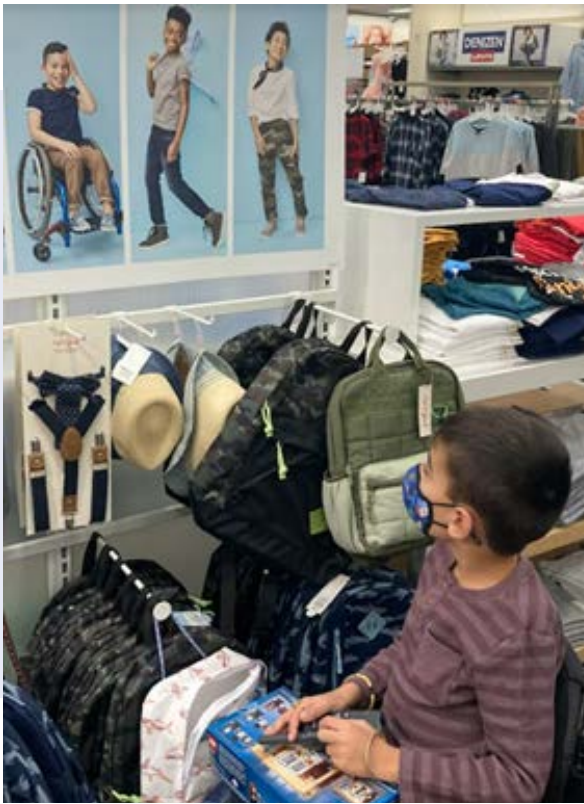
Key Finding 2.4: Children with chronic conditions may feel like they are excluded from and/or “behind” their peers.

Although the focus of this needs assessment was on the family as a whole, the effect of the condition on the children themselves became a recurring theme in Coming Into Focus and focus group portions of the needs assessment. When a child has a chronic condition they often miss out on experiences that their peers have. Sometimes this is financially motivated. As mentioned previously, many families cannot afford vacations or extracurricular activities. Children also missed large periods of school, putting them behind their peers academically or developmentally. In addition, feelings of exclusion are caused by constant exposure to environments that are not built to meet a child's needs.

Through Coming Into Focus, it became clear that being able to “be a regular kid” plays a big part in how children perceive themselves. In their own voices, youth co-researchers captioned photos reflecting that impact on their self-perception.

“In school, I am always held back by a chain of questions about my diabetes. Can you? Should you? Is that OK? I am trapped. I can't leave.”





"I don't usually see kids in wheelchairs in advertisements. It made me happy to see this."

This need was also evident in our conversations with young adults. One young adult participant shared how having people be "not weird" about her condition was important to her. "Having people who want to learn where those limits are and how they can still include you in things without overworking you and being willing to put in that time. Knowing people who do that is a really big part of just feeling well in day-to-day life. You don't end up overworking yourself, and you don't end up totally isolated."

Indeed, caregivers shared that the feelings of exclusion from their peers can cause emotional and mental health distress in their children. One focus group caregiver talked about obtaining mental health services for their child "just to help him process the grief, the loss that he's basically lost his childhood." Another caregiver emphasized the importance of recreational activities: ". . . Those things were really helpful to lift him up and just make him feel like he's not just a disease or he's not just sick, but he's actually this full human being with other interests and thoughts. So yes, it's not even that it's just fun activities, but there are things that help build him up, build the kid up."

"Sometimes I feel like I can never be as healthy as all of my friends are. You may think that it sounds like I'm this kid that can't do anything and just sits around all day and should be said, 'Poor you' to. But that's not true. At the end of day, I'm just an ordinary girl who loves reading good books and playing with my American Girl dolls."



Key Finding 2.5: Siblings of children with chronic conditions often are in need of services that address their emotional and mental health needs.

Throughout the key informant interviews and focus groups, it was clear that siblings often feel that they are lacking attention or care from caregivers and sometimes even have the burden of providing child care or medical care for their sibling(s). It was often expressed that there is a need for mental health services to address the emotional impact on siblings.

Key informant participants identified a need for sibling support groups and how siblings sometimes are forced to "take a back seat" in terms of caregiver attention. They also described how siblings are often put in caregiving roles due to lack of available services. One provider shared, "I have had situations where a family with a very complex child had a trach, and the sibling had to take care of that child for part of the day because they couldn't get nursing."

Focus group participants also identified the impact their child's chronic condition has had on their other children. Often, caregivers shared remorse and guilt for the effect on their relationships with their other children. One caregiver lamented, "For my son and I, quality time right now has been really strained because I have had such burnout lately . . . There's just kind of been a disconnect between us. I want to get us back on track." Other caregivers expressed that the impact on their other children was not taken into consideration until after critical periods of their child's condition had passed: "I didn't realize how our child affected the rest of our family. We were so busy trying to survive and get him to live that we put all of these burdens on our other kids, and that was eye-opening for us."



“My son and daughter were having trouble communicating. He ended up laying in his bed crying and asked me, ‘When will things get easier?’ This is the impact that disabilities and chronic illnesses have on siblings. The lack of supports for us as parents makes it hard to juggle everything. We struggle to support them, simply because there aren’t any resources available or it isn’t financially possible. Families like ours need change to thrive.”

Feelings of resentment were common among siblings, according to caregivers. As one participant explained, “It impacts because your other children get invited to birthday parties and different events. And sometimes if you can’t find coverage for somebody to stay with your daughter or to bring your other kids to an event, they have to miss out. And then there’s that the siblings end up having issues and they start blaming things on the child that’s ill that doesn’t want to be ill.”

Research Objective 3: Describe both the supportive and challenging features of the current continuum of care (community-based, clinical, etc.) to support children with chronic conditions, their caregivers, and their families. Describe strengths and challenges in accessing a comprehensive range of services to support families managing a youth’s chronic condition.

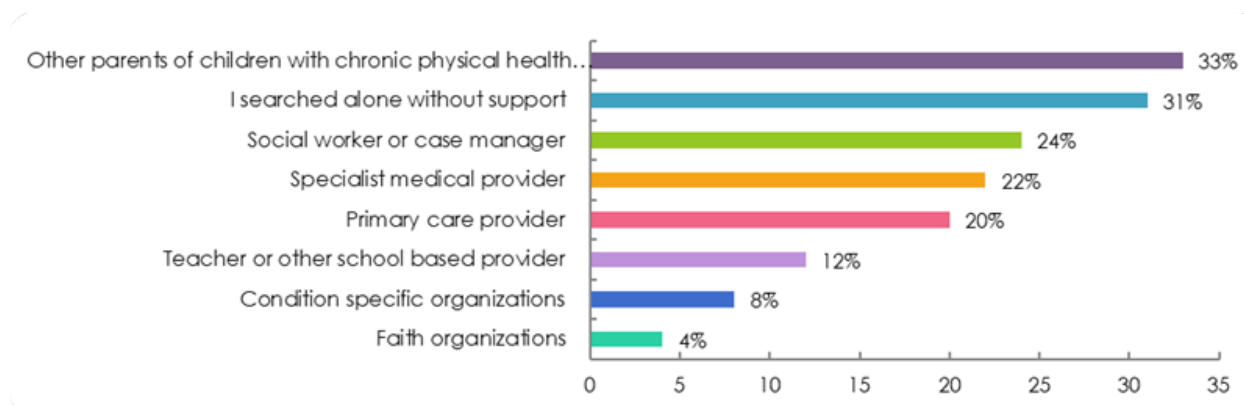
I feel like every agency and division and whatnot in the state of New Hampshire is so siloed in little; I’m not going to talk to this one, and this one’s not going to talk to that one, and that one’s not going to talk to that one. So you have to tell your story, your kids’ story, 60 different times to get 60 different results or fill out 60 different applications or request 60 different medical releases to the 60 different people.

—focus group participant

Key Finding 3.1: Families have trouble navigating and understanding what is available to them in a complex and disjointed system of services and supports.

The final question posed during the focus groups was, “If you could wave a magic wand, what would you change about the current supports and services offered to families of children with chronic physical health conditions?” Overwhelmingly, participants’ replies mentioned someone to help navigate the services and supports available to them and a streamlining of application and approval processes. As seen in Figure 8, survey responses echo this, with the top entities cited as helping respondents search for services and supports being other parents of children with chronic physical health conditions and the respondents themselves, followed by a social worker or case manager. This was observed in focus groups where often, in the process of discussing a focus group question, participants began to share information about programs and tips and tricks for navigating systems among each other.

Figure 8. Who helped you in your search for services and supports for your family? (Select all that apply) (n=49)



Although not as prominent in the survey, condition-specific organizations were mentioned frequently in focus groups and key informant interviews as sources of information and support for families. Some key informant participants shared that while condition-specific organizations are filling a needed role for families, their prevalence could be contributing to silos between families, rather than encouraging cross collaboration in advocating for needs. Many families mentioned that Partners In Health was extremely helpful navigating the system but that the way they discovered the program was through happenstance or other parents. As one focus group participant put it, “I struggled for five-and-a-half years dealing with my son going for cancer treatments with no help because I never knew about Partners In Health. Nobody ever told me anything about it. It was a chance encounter . . . and what a change in my life since meeting [the Partners In Health coordinator] and finding out about Partners In Health. What I struggled through for five-and-a-half years, in the six months’ time that she helped us, what a difference.” A few families participating in focus groups were unaware that Partners In Health was a service available to them.

Even if a family is enrolled in a service or support, navigating it remains difficult. For example, both focus group participants and key informant interviewees emphasized challenges understanding aspects of the insurance system, such as eligibility criteria and the services that are covered as well as the extensive time spent communicating with insurance companies about covering services. Eligibility renewals were also cited as challenging and time-consuming processes in which families must repetitively communicate the same information about their family.

From a systems perspective, key informant participants reported as challenges in service navigation and delivery poor communication of available resources and services, the high burden of paperwork on families, a lack of data sharing/interoperability across systems, and a lack of communication between service organizations. One key informant challenged the notion that what is available to families of children with chronic physical health conditions could be called a system, stating, “I don’t feel it’s a system. It’s funny when you say that. I think kiddos with chronic illness don’t really have a system.”

Key Finding 3.2: Families do not universally experience family-centered care.

In the community survey, JSI/CHI provided a definition of family-centered care as a way of providing services that ensures the health and well-being of children and their families through respectful family/professional partnerships. It honors the strengths, cultures, traditions, and expertise that families and professionals bring to this relationship. Based on this definition, the majority of caregivers (73%, n=48) responded that they did not receive family-centered care in the past 12 months.

Patient-provider relationships also emerged as a common theme from key informant interviews. Key informant participants defined a positive patient-provider relationship as one where there is trust between families and providers and a sense of working together for the child’s benefit. As one provider put it, “We may not be able to use our wand to fix it all, but we’ll work together with you and try to do the things that we can do to support you through it So, I think honesty and humbleness about the realities that they’re facing that we’re facing, too. We can’t fix it all, but we can certainly try.” Often providers become advocates for the families, especially in regards to insurance coverage. Key informant participants defined a negative patient-provider relationship as one that often led to misunderstandings. In these relationships, there is a lack of family-friendly language, an assumption that the family understands their loved one’s medical needs, and a pronounced disconnect and lack of communication between providers and other supports. Key informant participants cited staff turnover and lack of communication across health systems as contributing to negative patient-provider relationships.

Families in focus groups echoed how critical it was to have a positive patient-provider relationship. One caregiver expressed frustration at finding providers who understand their child’s condition: “The big thing is that many of the doctors, social workers, and counselors, occasionally you’ll get someone who just gets it, but they lack curiosity. They also lack the training to work with someone of my child’s complexities.” Others mentioned health care providers when talking about services and supports that they found helpful. A focus group participant underscored the

importance of a good primary care provider for her daughter, saying, “When we found a PCP that was supportive, that was the biggest support that we have ever gotten in my daughter’s complex, rare conditions . . . She supported my daughter so much because she did look at all that other stuff, where we’d spent all the other years going to all the individual specialists and traveling all around. So, finding a really good supportive PCP and having that doctor help create the team to support your child with your specialists was life-changing for her.”

“They said she would never be able to hear, see, interact, or even know who we were other than a stranger. Her physical therapist brought her this switch hooked up to this fiber-optic light that turns on when she hits the switch. If she holds it down, it will change color. We thoroughly enjoy watching Isabelle develop and do things the medical field told us her brain would never do.”



Key Finding 3.3: Many access school-based services, but support does not always meet their needs.

Of the many systems with which families interact, schools and school-based health services frequently emerged both as a source of support and a source of stress. The majority of survey respondents whose child with a chronic physical health condition was older than age 3 had them enrolled in a public school, and 69% of respondents said their child received additional support and services in the school setting. The most common types of school-based services were Individualized Education Plans (IEP); 504 plans; paraprofessionals; and speech, occupational, and/or physical therapy. The majority of survey respondents felt their child's school, teacher, and service offered enough support and accommodations to help in the management of their child's condition.

However, a more challenging relationship with schools emerged in the key informant interviews and focus groups. Both providers and caregivers mentioned struggles in getting children the assistance and accommodations they need. Common examples included difficulties such as the following:

- Having the school nurse administer medication. Sometimes schools requested parents come in to administer the medication instead.
- Misunderstandings in the accommodations needed for the child, such as periodic breaks or modifications for physical education.
- Obtaining tutoring or home-based services during which a child has to miss school for long periods of time due to treatment or illness.

One focus group participant shared the challenges their family faced in communicating their child's 504 plan: "I see [the 504 plan] as just a backup so that when I do need to advocate, I can say, 'Hey, her 504 plan says this.' . . . Some of the teachers didn't know about it until I brought it to their attention. I was doing an email at the beginning of each school year. 'By the way, our child has accommodations to use the bathroom when she needs to. She needs to have access to the water bottle. She had kidney cancer, so she only has one kidney.'" The one adolescent focus group participant also reported having to advocate for themselves using their IEP and 504 plan, demonstrating that the burden to ensure proper accommodations in school can fall on the child as well as caregivers.

Key Finding 3.4: Health care transition services for young adults and adolescents are extremely beneficial but often lacking.

Advances in science and the medical field mean more children with chronic physical health conditions are able to grow into adulthood and lead fulfilling lives. The health care system that supports these adolescents and young adults, however, has struggled to adapt specialities that were typically pediatric and help patients transition into care that they direct and coordinate instead of their caregivers. As one provider explained in a key informant interview, "A lot of the practicing providers trained before kids survived into adulthood, so we have this knowledge gap There's a wealth of young people with medical complexity whose medical technology has advanced as they were aging, but the training for all the adult providers isn't moving as quickly."

Of the 23 survey respondents who had children ages 14 and older, 78% reported not having received services needed for transition to adult health care. This is especially concerning given that best practices emphasize having conversations to start the process early on. The organization Got Transition (2022) has Six Core Elements of Health Care Transition,TM and the timeline for implementation starts when the child is age 12.

In a focus group focused on young adults, participants who had received health care transition support shared that they were confident in accessing health care services without parental help. They also shared insights on the challenges of health care considerations as they become more independent. As one focus group participant reflected on peers who may not have received the same level of health care transition support that they did explained, "That transition to college is

huge These kids are also taking on huge medical risks when they're going off. For example, kids with seizure disorders take, in perspective, they're sitting there, thinking, 'What happens if I have a seizure with this total stranger of a roommate?' Those aren't your normal things you think about when you're going off to college. So, it's a totally different mindset that they have to think about. And so, providing more supports and services around, how do you prep for that? How do you have conversations with a new roommate around, 'Here's my medical complexities?'"

Key Finding 3.5: Many families lack access to the services they need due to lack of eligibility and availability.

Across data collection activities, two types of services were frequently cited as a priority need for families that were often inaccessible due to a lack of available providers and programs:

1. Professional caregiving assistance: Seventy-nine percent of survey respondents said they did not have reliable access to respite care, defined as when a professional caregiver gives someone a temporary break (as short as a few hours) from primary caregiving (n=53). Ninety percent of survey respondents also said that their child received no form of outside child care such as the type offered through after-school programs, a babysitter, or a child care center (n=49). High cost and an inability to find providers that could manage their child's condition were the most frequent reasons for being unable to obtain child care. The lack of these types of care was also cited in focus groups and key informant interviews as well as an inability to obtain any or adequate in-home nursing services. As one provider explained, "A lot of families, in terms of respite . . . just don't have a break just because nobody feels competent to take care of them. And nursing care, how many families have 40 hours, and they're lucky to get five or 10?"
2. Mental health services: This need emerged strongly in focus groups and key informant interviews as a critical need for all members of the family. As one provider explained, "There just aren't enough, period. Again, that's not specific to children and families with special health care needs. It applies to everybody, but it's even worse for those families with special health care needs. And then add in some of the other challenges that some of these families face, whether it be geographic, financial, cultural, whatever the scenarios are. That's a clear deficit that I'm not sure that there is any major light at the end of that tunnel at the moment, but that's certainly a big issue." Focus group participants shared experiences of waiting months for appointments for their children and sometimes never getting to see one. "And at some point, people just give up, or they forget about it, and they're like, 'Eh.' Or my daughter may seem OK now. And then she may be really not [OK]."

For both professional caregiving assistance and mental health services, workforce shortages were emphasized by participants in almost every key informant interview. For example, families whose child has a chronic physical health condition but no developmental disabilities often do not qualify for financial assistance with respite care. To compound the problem, they would have difficulty in obtaining the care even if they could financially afford it due to limited workforce in the field.

In addition to these types of services, in general, families often are unable to access needed services such as financial assistance and housing due to eligibility requirements. This “benefits cliff” has been reported as a phenomenon for many families in NH regardless of health status (Econsult Solutions, 2021), but it is particularly concerning for families of children with a chronic physical health condition. As one focus group participant put it when describing how they were told they fell through the cracks in terms of service eligibility, “. . . The cracks, they’re not cracks, they’re canyons. And there’s a lot of families at the bottom of those canyons because if there’s one like me, you know there’s at least probably in my city, two or three dozen more.”

Research Objective 4: Identify communities with greater need and the unique challenges they face.

JSI/CHI made the decision not to stratify survey data by demographics given the small convenience sample. However, through key informant interviews and focus groups, several populations and communities emerged as groups who may face added challenges in managing their child’s chronic condition.

Families with one caregiver

Key informant interviews frequently mentioned families in which there is only one caregiver, most commonly a mother, as a group that struggle more in getting the services and supports they need. One provider explained, “The single moms. Predominantly, more single moms than single dads, certainly are outnumbered by the challenges of caring for someone who is medically complex, especially if they’re not the only child, then you don’t have enough adults in the household to go around.” This same provider shared that the vast majority of cases they have had where the caregiver was in critical mental health distress involved single mothers. One focus group participant who identified as a single mother leveraged extended family for support, stating, “I became a single parent to the boys, and I just can’t do too much to help [child] because I obviously have [chronic condition], too. And if my mom didn’t live here, I don’t know what I would do.”

Families with difficulty communicating in English

Key informant participants often mentioned families whose primary language is not English as families they are particularly concerned about not getting the services and supports they need. One provider serving the Manchester area explained, “In my area, language is a barrier. There’s lots of immigrants and refugees. And so, coming here to learn the different systems that are available and then having that language barrier is difficult. They need someone more than a typical family, and so a lot of my time is spent with those families because they need an interpreter or they need something translated, and there’s not services available like that for those families.” In the 2022 NH State Health Assessment, community researchers documented these experiences in several listening sessions with Spanish and Portuguese-speaking families, although these families were not specifically managing chronic conditions. As of this report’s writing, that summary is not yet publicly available; it will be posted to www.NHLivesWell.org in fall 2022.

Immigrant/refugee communities

Key informant participants also frequently mentioned immigrant and refugee communities. Beyond language barriers, one provider who works with refugee communities observed, "It's a trust and access problem We've had, I think it's safe to say, both parents and organizations that are resistant sometimes to either getting help or giving help where it's needed." Key informant participants also shared that transportation, getting time off of work to attend appointments, and accessing or qualifying for supports such as SNAP can also be a challenge for these communities. These themes were also reflected in the 2022 NH State Health Assessment, referenced above.

Grandparents

Key informant participants also identified grandparents who are raising their grandchildren as needing additional support in part, because there is hesitation in accessing resources due to stigma or lack of awareness of what is available to them. As one key informant participant shared, "I think the older generation grandparents, not having needed to rely on resources, maybe raising their own children, because that's the generation that they come from. But now raising this next generation, everything is more expensive and different and resources are different. I don't know if it's as much accessing or if it's more realizing that the resources are available"

Families living in rural areas

Families living in rural areas face challenges with transportation, access to providers, and technology. One key informant participant serving families in the North Country region of NH explained how these challenges become barriers to care: "The traveling expenses, the cost of repairs, keeping a vehicle that you can afford on the road and accessible. I think another thing up here is technology. Everybody assumes you can do a Zoom meeting or you can connect, it is just not the case here. You know, most times it's families just can't afford it. They can't afford that extra cost of getting technology into their home." Focus group participants from rural areas also shared anxiety about transportation: "Driving is always an issue, especially in the winter. And we have to really pay attention to whether the car is working or not. And so yeah, that has been a real problem to have transportation and communication, the phone working, everything has to be set up so that [child] can get to a hospital if she gets a fever."

RECOMMENDED AREAS OF FOCUS FOR CYCC

Children, siblings, and caregivers—all need more access to financial support, a comprehensive and navigable system of interconnected services, and social and recreational opportunities in a timely manner. In order to help CYCC organize its efforts to strengthen the continuum of care available to meet these needs, JSI/CHI has developed the below list of recommendations based on this needs assessment's key findings.

The deeply-rooted systemic challenges nonprofits across the state work to address often require a great deal of capital - financial, human, and social. As such, JSI/CHI appreciate that nonprofits often have to make difficult choices on where to strategically allocate the resources available to them. These recommendations are intended to provide some guidance as to where CYCC may look to focus its energy, or choose to leverage partnerships with similarly focused organizations to help elevate the voices and experiences of the families they aim to serve. While these recommendations were categorized into partnership and advocacy opportunities, JSI/CHI recognizes that these approaches often intersect and support each other.

Strategic Partnerships Systems-level change requires buy-in and collaboration from a variety of stakeholders. CYCC may consider playing a convening role to continue and expand partnerships with healthcare and respite/ancillary providers, state agencies and other nonprofits to:

- **Collaborate with and promote services such as Partners In Health.** CYCC currently works closely with services like Partners in Health to promote their existence to families in need. Most of the families engaged in the needs assessment were connected in some capacity to existing supports and services. It is unclear how many families in NH are unconnected and struggling on their own with their child's condition. Therefore, CYCC's continued dissemination of available services across the state is critical.
- **Engage schools.** This needs assessment identified the need for school-based services and supports, including school nursing and referral services. CYCC could work with the NH Department of Education and school districts to identify gaps and strengthen the current supports offered.
- **Incorporate different dimensions of diversity into engagement and recruitment efforts.** CYCC's current Advisory Council and leadership group reflects a diversity in experiences, as related to health conditions. However, given the role intersectionality plays in how families experience the health care and social support system, an opportunity exists to strengthen efforts to focus engagement with communities (and agencies serving those communities) who have other racial, ethnic, cultural backgrounds and different family structures. Fathers and other types of caregivers could also be further engaged using similar methods used in the needs assessment (recruiting through mothers, word of mouth, father to father recruitment).
- **Identify ways to support communities with unique needs.** CYCC could strengthen existing, and identify new partnerships with organizations working with rural communities, single caregiver households, grandparents, immigrant/refugee communities and families who have difficulty communicating in English. Examples include agencies who employ kinship navigators, rural health consortiums, and immigrant/refugee serving groups.

Advocacy Many of these issues identified in this needs assessment - including the availability of providers, cost of care, community accessibility - require systemic solutions initiated by legislative and administrative efforts. CYCC might consider its role and contributions to these systemic solutions and explore supporting advocacy efforts aimed at:

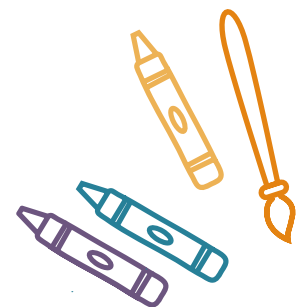
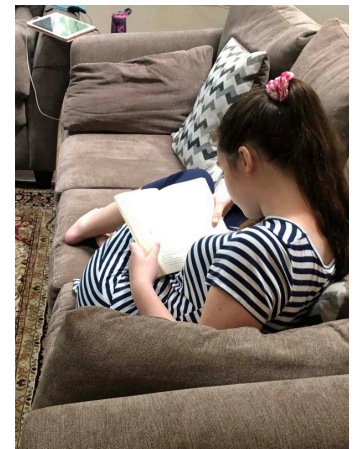
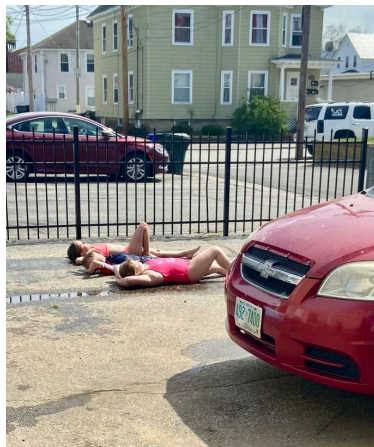
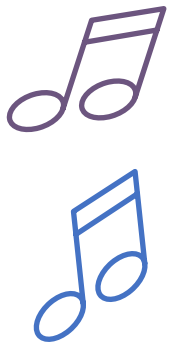
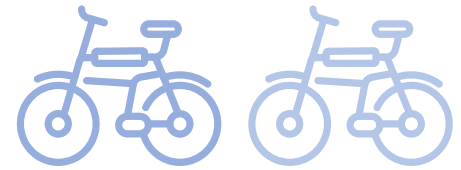
- **Improving the interoperability of data systems to streamline how families are supported, and how families are able to access services.** Both providers and caregivers mentioned the silos in which data about families exist. This needs assessment itself was impacted by the lack of data available about the focus group population. CYCC is already partnering with state agencies and other stakeholders to problem-solve around data interoperability and improved databases and should continue to explore and promote innovative approaches to this issue.
- **Strengthening the healthcare workforce supporting families (behavioral health, home health, respite, etc.).** Many advocacy groups across the state are working to strengthen the healthcare workforce by trying to address a number of issues - reimbursement rates, education costs, and licensing rules - to expand the ability of providers to give care. CYCC may explore how it can leverage its resources to support or engage in any of those efforts.
- **Promoting the need for more accessible communities.** One way to combat the feelings of isolation and exclusion families are feeling is for CYCC to continue to partner with disability rights organizations to make leaders, businesses, and policymakers aware of the importance of accessibility in spaces for families, such as, for example, playgrounds, accessible shopping carts in grocery stores, and accessible recreation equipment in schools and other spaces.
- **Creating a better integrated, comprehensive system of services and benefits for families.** Throughout the needs assessment, it was clear that families who qualify for area agency services receive additional supports for which most families of children with solely a chronic physical health condition do not qualify. CYCC could advocate for an expansion of services and benefits to begin to meet the critical needs families reported over and over again, such as financial assistance, care coordination, social/recreational opportunities and caregiving support and a streamlined application process. This expansion could also benefit families whose children have both developmental and physical health conditions.

CONCLUSION

This needs assessment aimed to provide a more 360-degree view of what it is like for a family in NH to raise a child with a chronic physical health condition than previously attempted and highlighted a population who can easily fall between the cracks in the current fragmented system of family-focused services and supports. It is evident from the experiences shared by families in the needs assessment that a health condition goes beyond the direct medical consequences for the child and affects every family member and every aspect of family life, including finances, relationships, emotional and mental health, education, and daily life. Many of these challenges and their causes are systemic in nature and broadly felt by families in NH, regardless of health status. But when a family is also facing the fear and uncertainty of their child's health, these challenges can have especially damaging effects. These families who tirelessly advocate in every appointment and setting on behalf of themselves and their children often do not have a vehicle through which to communicate their needs to a wider audience.

CYCC can serve to amplify their voices and coordinate with state and nonprofit entities to improve the network of support available to them.

The needs of families of children with chronic physical health conditions can feel overwhelming. However, these are also families who, like any other, experience moments of immense gratitude, happiness, and unity in the midst of day-to-day life. To close this needs assessment with a focus on their strengths, the image below captures the variety of answers we received during this process that highlight the joys families experience:



ACKNOWLEDGEMENTS

JSI/CHI would like to acknowledge the contributions from the advisory council and greater CYCC community. The opportunity to collaborate with parents and caregivers with lived experience to design this needs assessment was invaluable. JSI/CHI would also like to thank the network of organizations serving these families who assisted in recruitment and dissemination.

Most of all, JSI/CHI would like to thank the families who participated in this needs assessment, either as Coming Into Focus co-researchers, survey takers, or focus group participants. JSI/CHI is grateful for their contributions and input and honored to have been able to amplify their voices.

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Rogers, M. A., Rogers, B. S., & Basu, T. (2018). Prevalence of type 1 diabetes among people aged 19 and younger in the United States. *Preventing Chronic Disease*, 15, 180323. Retrieved September 27, 2022, from https://www.cdc.gov/pcd/issues/2018/18_0323.htm#table1_down

APPENDICES

Appendix A: Community Survey Data Summary

Appendix B: Key Informant Interview Questions

Appendix C: Key Informant Interviews Qualitative Coding Scheme

Appendix D: Focus Group Interview Questions

Appendix E: Focus Groups Qualitative Coding Scheme

Appendix A: Community Survey Data Summary

All Survey Respondents (n=67)

Survey Language Selection (n=67)

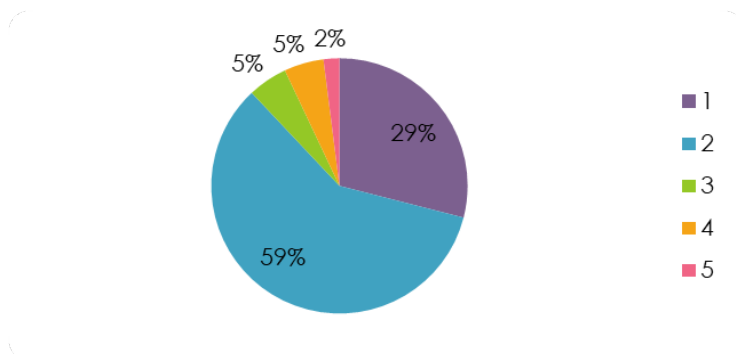
Value	Percent	Count
English	100%	67

Caregivers vs. Young Adult Survey Respondents (n=67)

Value	Percent	Count
Caregiver 18 years or older of a youth under 21 with chronic physical health condition(s)	88%	59
Young Adult (18-21) with a chronic physical health condition(s) living with my family	7%	5
Young Adult (18-21) with a chronic physical health condition(s) living independently	5%	3
	Total:	67

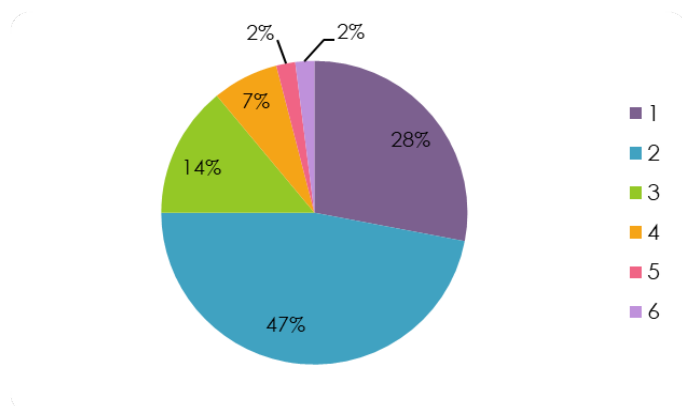
Caregiver Survey Respondents

Number of Adults Currently Living in Survey Respondent's Household (n=59)



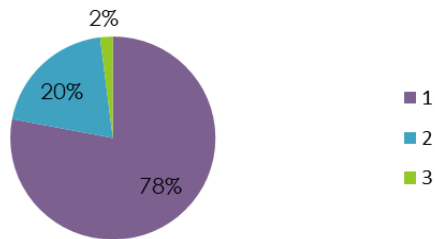
Value	Percent	Count
1	29%	17
2	59%	35
3	5%	3
4	5%	3
5	2%	1
	Total:	59
	Mean:	2

Number of Children Under the Age of 21 Currently Living in Survey Respondent's Household (n=57)



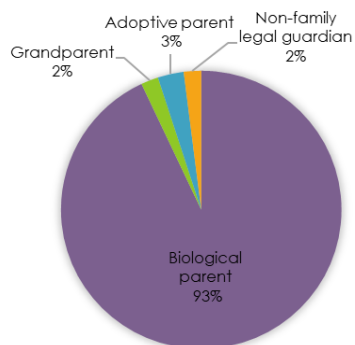
Value	Percent	Count
1	28%	16
2	47%	27
3	14%	8
4	7%	4
5	2%	1
6	2%	1
	Total:	57
	Mean:	2

Number of Children Under the Age of 21 with a Chronic Physical Health Condition(s) Living in Survey Respondent's Household (n=59)



Value	Percent	Count
1	78%	46
2	20%	12
3	2%	1
Total:		59
Mean:		1

Survey Respondent's Relationship to the Child(ren) with a Chronic Physical Health Condition(s) (n=59)



Value	Percent	Count
Biological parent	93%	55
Adoptive parent	3%	2
Grandparent	2%	1
Non-family legal guardian	2%	1
Total:		59

Age of Survey Respondent's Child(ren) with a Chronic Physical Health Condition(s) (n=57)

Mean Age: 11 years

Most Frequent Age (Mode): 14 years

Maximum Age: 19 years

Minimum Age: < 1 year

Chronic Physical Health Condition(s) of Children (n=59)

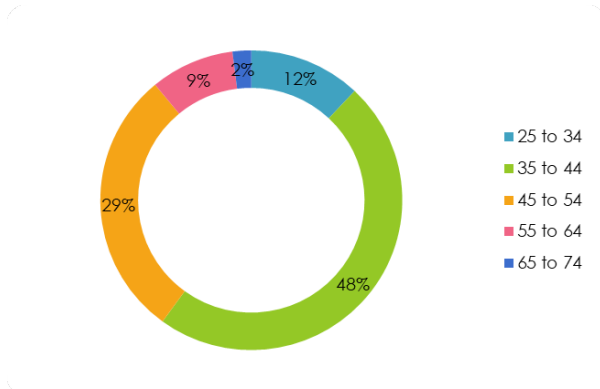
Condition	Count*
Asthma	21
Autoimmune conditions	14
Diabetes	10
Neuromotor conditions (e.g., spina bifida or muscular dystrophy)	10
Epilepsy	8
Congenital heart conditions	7
Cancer	6
Blood related conditions (e.g., hemophilia)	4
Cystic fibrosis	2
Kidney disease	3
Gastrointestinal/digestive disorder	3
Visual impairment	2
Hearing impairment	1
<i>Other chronic physical health condition (e.g., connective tissue disorder, immunodeficiency)</i>	13

*Total exceeds response n of 59 because this survey item allowed respondents to select multiple chronic conditions

Child(ren) who has/have a chronic physical health condition(s) eligible for or receiving area agency services? (n=59)¹

Value	Percent	Count
No	88%	52
Yes	12%	7
	Total:	59

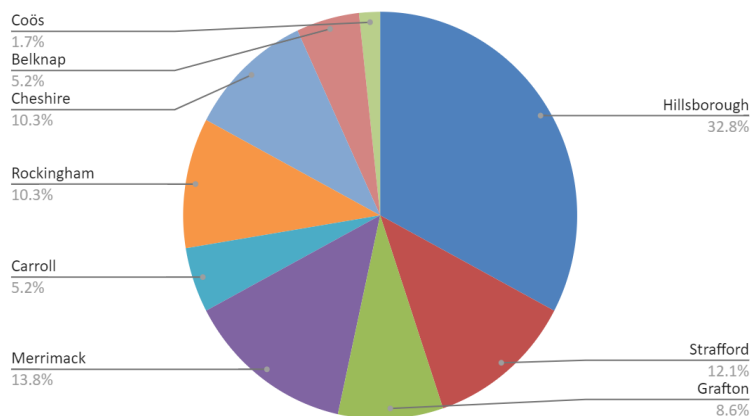
Age of Survey Respondents (n=58)



Survey Respondents' Town of Residence (n=53)

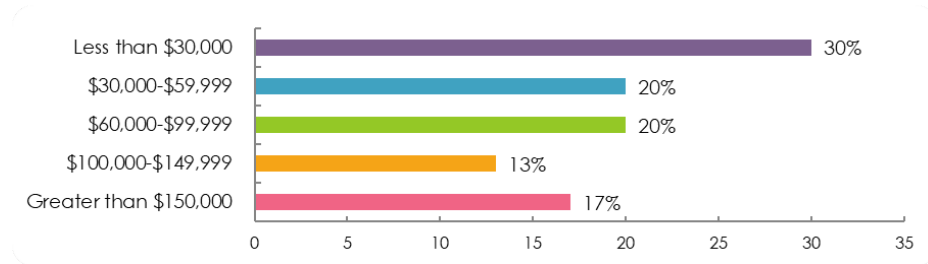
- 36 unique towns represented
- 9 unique counties represented

Survey Responses by NH County

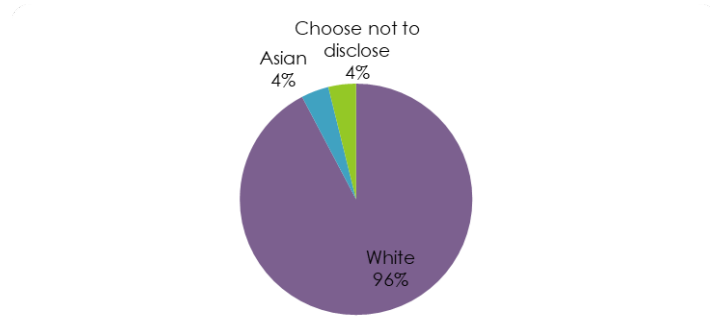


¹ This survey item was initially included as a screening question. In reviewing survey responses, the team determined that respondents experienced confusion around the meaning of 'area agency services', confusing it with Partners in Health services. JSI/CHI reviewed this survey item's data and compared it with responses to the survey item about the child(ren)'s chronic conditions. Survey responses that included a report of a developmental condition were removed from the dataset. Seven total survey responses met the inclusion criteria.

How much money did you or your family receive from all sources in 2021? Please include income from paid jobs, alimony/child support, insurance benefits, etc. (n=57)

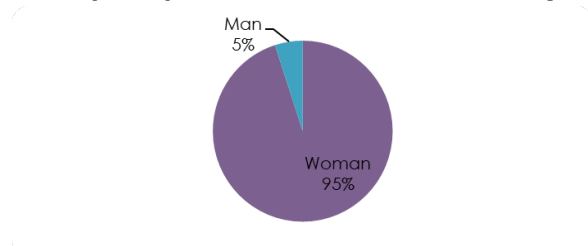


Survey Respondents' Race and Ethnicity (n=59)



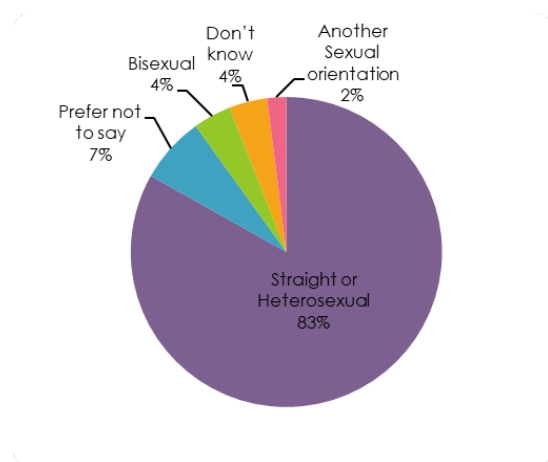
Value	Percent	Count
White	97%	55
Asian	4%	2
Choose not to disclose	4%	2
	Total:	59

Survey Respondents' Current Gender (n=57)



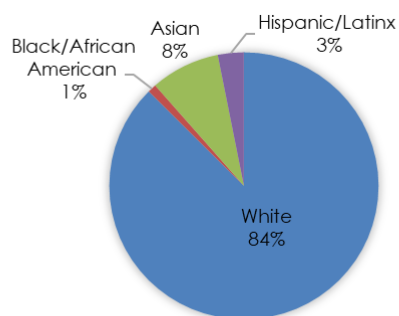
Value	Percent	Count
Woman	95%	54
Man	5%	3
	Total:	57

Survey Respondents' Sexual Orientation (n=57)



Value	Percent	Count
Straight or Heterosexual	84%	48
Prefer not to say	7%	4
Bisexual	4%	2
Don't know	4%	2
Another sexual orientation (e.g., pansexual, asexual)	2%	1
	Total:	57

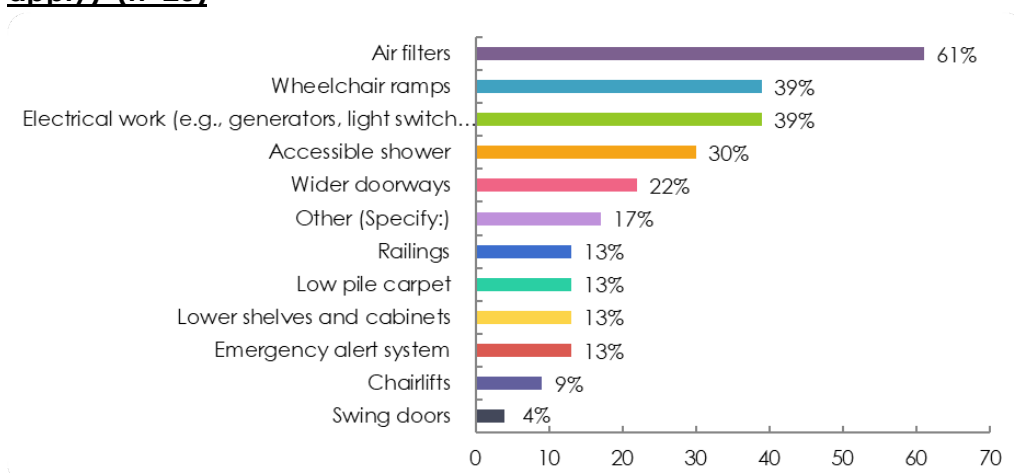
Child(ren) with Chronic Physical Health Condition(s)' Race and Ethnicity



Value	Percent	Count*
White	84%	65
Black/African American	1%	1
Asian	8%	6
Hispanic/Latinx	3%	2
Choose not to disclose	4%	3

*Total exceeds total survey response n of 59 because this survey item allowed respondents to select multiple chronic conditions

Please select any physical or structural changes you've made to your home to meet the needs of your child(ren)'s chronic physical health condition(s). (Select all that apply) (n=23)



Other (Specify:)

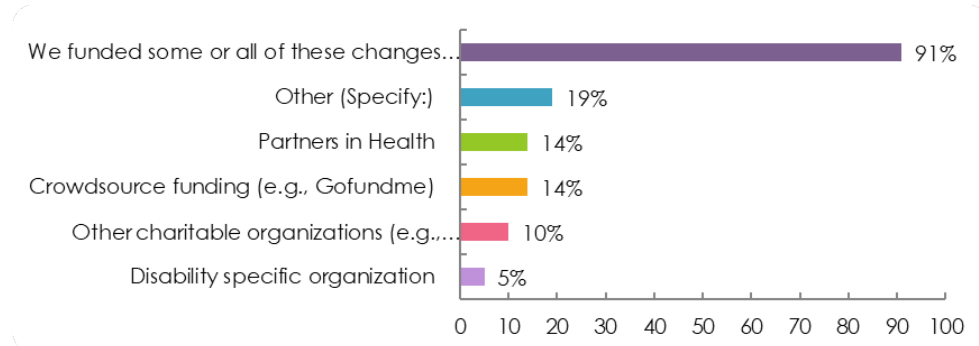
Air conditioning, specialty cleaning devices, screened outdoor structure

Grab rails

Changed some doorways to slide verses swing open

Mattress protectors

If you did make changes, who has helped pay for them? (Select all that apply) (n=21)



Other (Specify:)

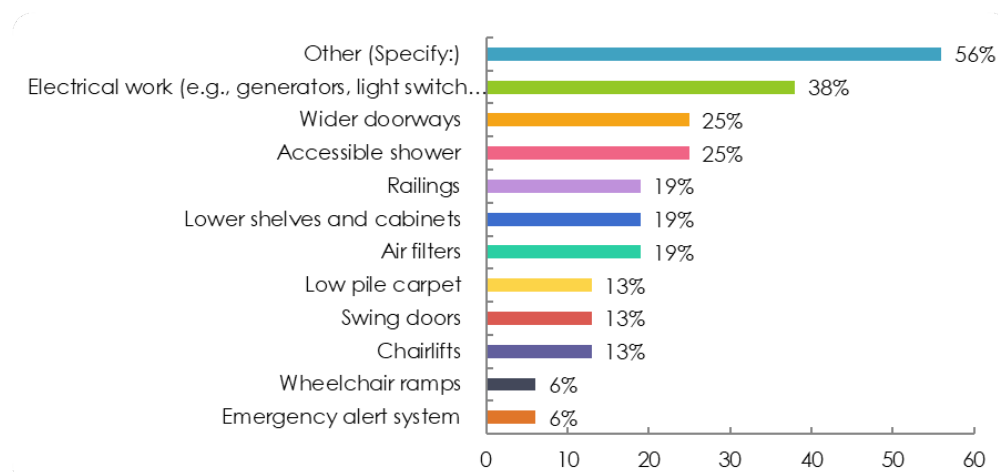
Area Agency

Help from friends/neighbors

Waiver fund

Wheelchair lift was funded through Area Agency when our son was in early intervention

Please select the physical or structural changes your home still needs to meet the needs of your child(ren)'s physical health condition(s). (Select all that apply) (n=16)



Other (Specify:)

Accessible sliding door (w/out a threshold) to back yard (primary egress b/c wheelchair lift is often malfunctioning)

Fence around the yard needs repair

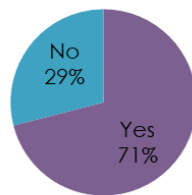
I rent, unable to make changes, need a home to better care for children

New floor to replace carpeting

Padded carpets

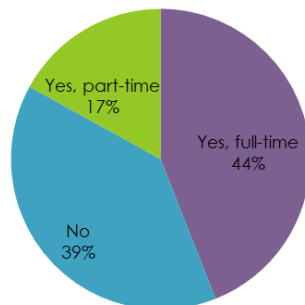
Shower needs replacing, the shower walls absorbing water
Shower - our shower walls are absorbing water and moisture causing mold
We're homeless, living in a hotel (paid for by CAP) but will likely need a wheelchair ramp wherever we end up
Wheelchair transportation
Window alarms, door alarms, anti-slam doors

Is the reason you haven't made these changes because your family needed financial support for these changes but was unable to get it? (n=21)



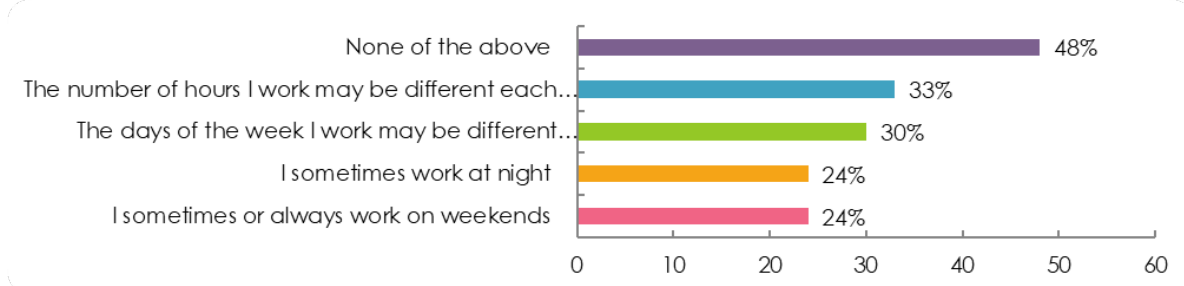
Value	Percent	Count
Yes	71%	15
No	29%	6
	Total:	21

Do you have a paid job? (n=54)



Value	Percent	Count
Yes, full-time	44%	24
No	39%	21
Yes, part-time	17%	9
	Total:	54

Which of the following applies to your current paid job? (Select all that apply) (n=33)



Value	Percent	Count*
None of the above	48%	16
The number of hours I work may be different each week	33%	11
The days of the week I work may be different each week	30%	10
I sometimes work at night	24%	8
I sometimes or always work on weekends	24%	8

*Total exceeds survey item response n of 33 because this survey item allowed respondents to select multiple response options

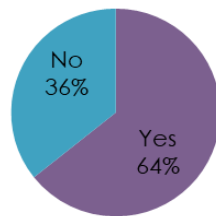
Due to your child(ren)'s chronic physical health condition(s), have you ever had to do any of the following? (Select all that apply and for the ones you select, specify if the change was temporary or permanent) (n=54)

	Temporary	Permanent	I have not had to do any of these
Take leave without pay	20	8	26
Change from full time to part time	13	14	25
Stop working	21	14	19

Change the days or time of day you work	16	14	23
Total Count*	70	50	93
% of Total	33%	23%	44%

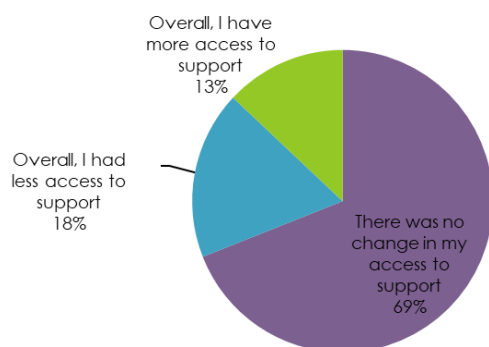
*Totals exceed survey item response n of 54 because this survey item allowed respondents to select multiple response options

Did these changes result in reduced employment benefits such as health insurance, dental insurance, and paid time off? (n=39)

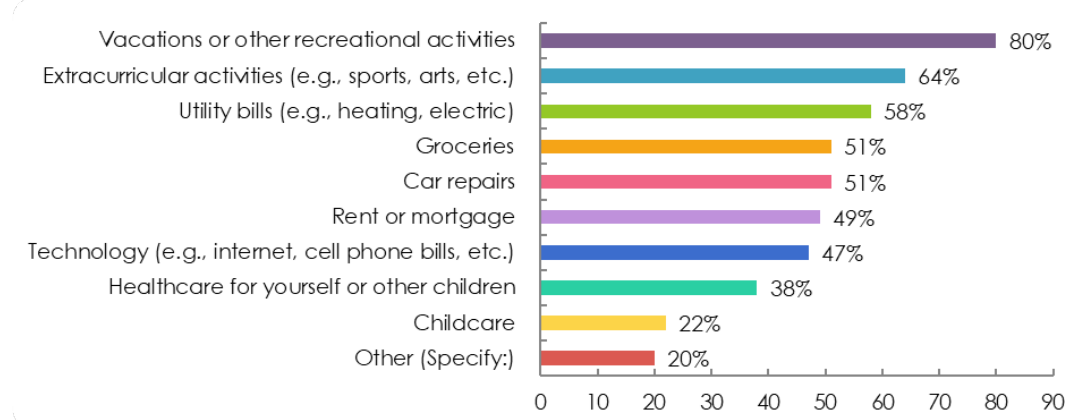


Value	Percent	Count
Yes	64%	25
No	36%	14
	Total:	39

How did these changes to your benefits affect your ability to get any other kinds of supportive programs or resources (e.g., charitable organizations, diagnosis specific associations, WIC, housing subsidy, Medicaid, etc.)? (n=39)

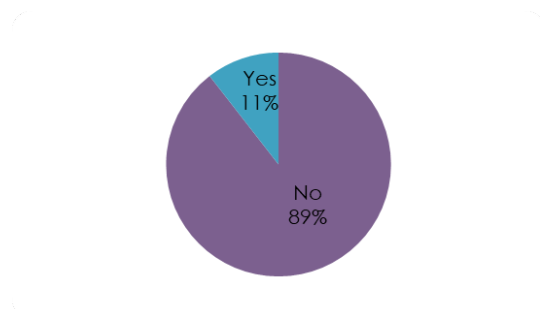


What kinds of items/services has your family, at times, had a hard time paying for or had not been able to pay for at all due to the costs involved in caring for your child(ren) with a chronic physical health condition(s)? (Select all that apply) (n=45)

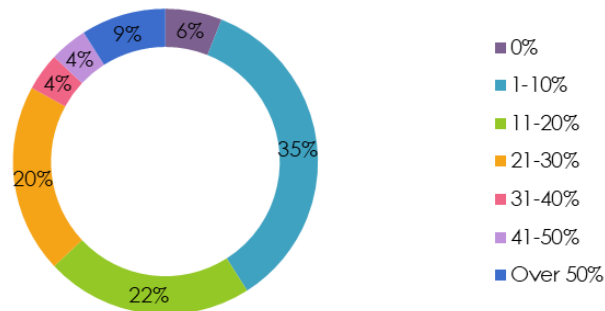


Other (Specify:)
A vehicle
Dental care, a home that would help our quality of life
Otc medications
Storage Units, gasoline to get her to appointments, etc.
Supplements
The special classes my child should be in
Transportation, clothing, laundry, moving expenses

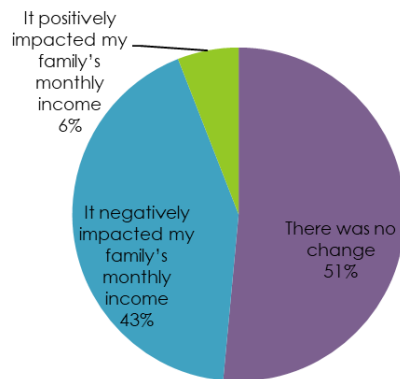
Has your family ever gotten financial support for needed medical expenses or other essentials through a crowdsourcing website like GoFundMe? (n=54)



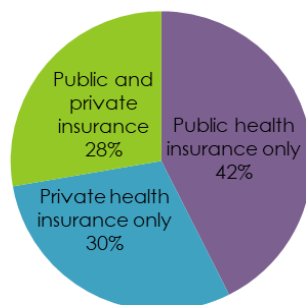
On average, in a month, what percentage of your household income are you spending to cover the cost of managing your child(ren) with a chronic physical health condition(s)? Examples include: co-pays, prescription and over-the-counter medications, home services, specialized transportation, educational supports, therapies, etc. (n=54)



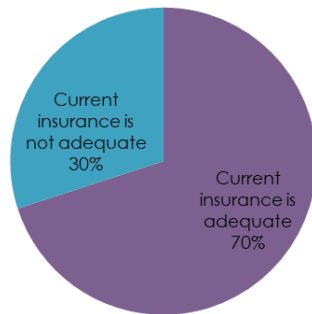
How has COVID-19 affected your family's income? (n=54)



What type of health insurance coverage, if any, did your child(ren) with chronic physical health conditions have at the time of the survey? (n=54)



Does your child(ren)'s current health insurance offer benefits or cover services that meet their needs? (n=54)



If not adequate, please list types of expenses that are NOT covered by insurance. (n=16)

Responses:

PT sessions(limited) and some meds

Some medications, rides to appt

Can't find providers to help

won't cover anything and deductible is 8,000 per person

Supplements. Adaptive equipment, safety equipment, communication devices, aquatic therapy, in home respite. Sensory devices, safe car seats

Having rare medical conditions means lack of tests or ability to bill insurance for life-saving supplements, medication's, amino acid nutrition support, travel expenses (from NH to NY every 2 weeks for appts) to specialists and so forth.

Amount of co-insurance on necessary medical devices creates significant financial burden for our family, and those devices are only now covered at the most expensive tier after two appeals to get them covered at all - they weren't originally on our insurance policy's formulary.

Specialized prosthetic legs are not covered by insurance that would improve my child's quality of life.

Otc medications and supplements. Travel expenses for doctors appointments, all things related to keeping infectious diseases out of our house. We also had to homeschool due to our child's medical condition and there was not any financial support. Prior to that we had her in private a school for her needs and there was no financial support was

Any and all over counter drugs, and alternative treatments

Two hours of therapy/wk at Project Walk. Since it's not provided by licensed PTs, it's not covered but it's the most effective and important two hours of therapy our son does each week (to the tune of \$240/wk). Hippo therapy is \$40 out-of-pocket/week.

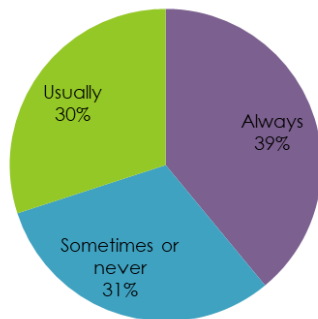
The amount of supplies we can get each month is very limited. We ran out of sensors for blood glucose readings and are not able to get them as soon as we need. We are still waiting (2 weeks)

Wheelchairs are currently only every five years - so frustrating because wear and tear and growth spurts, music therapy

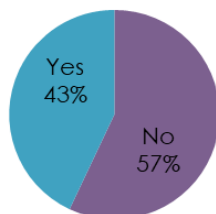
Transportation and restrictions on therapy

Vision, dental

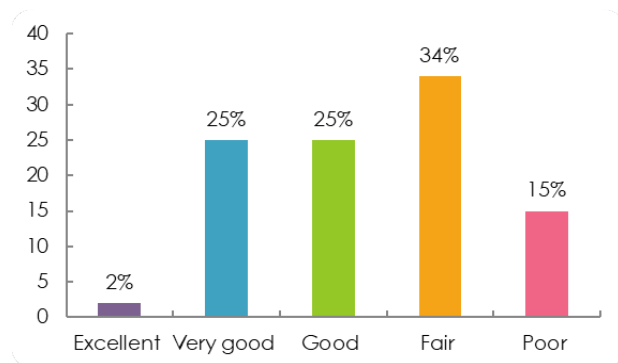
Thinking specifically about your child(ren)'s mental or behavioral health needs, how often does their health insurance offer benefits or cover services that meet these needs? (n=54)



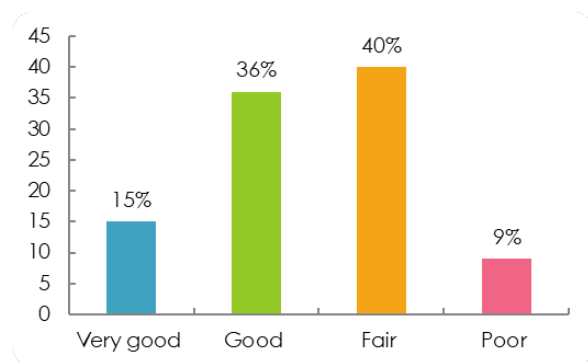
During the past 12 months, have you or other family members avoided changing jobs because of concerns about maintaining health insurance for your child(ren) with chronic physical health conditions? (n=54)



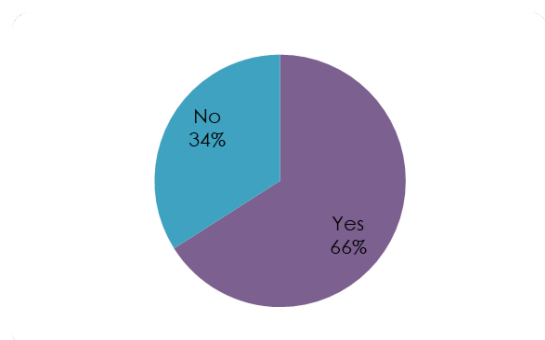
How would you rate your physical health status in general? (n=53)



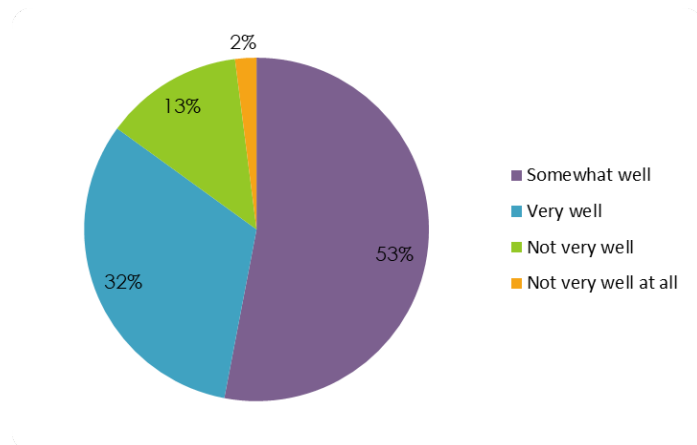
How would you rate your mental and emotional health status? (n=53)



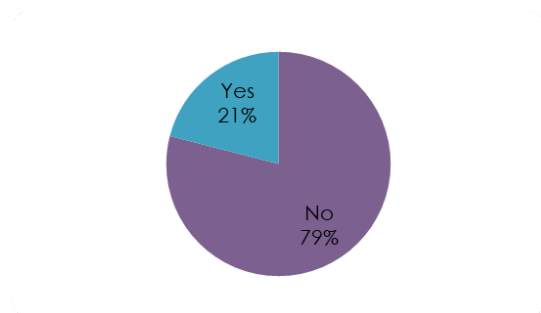
During the past 12 months, was there someone that you could turn to for day-to-day emotional support with parenting or caregiving? (n=53)



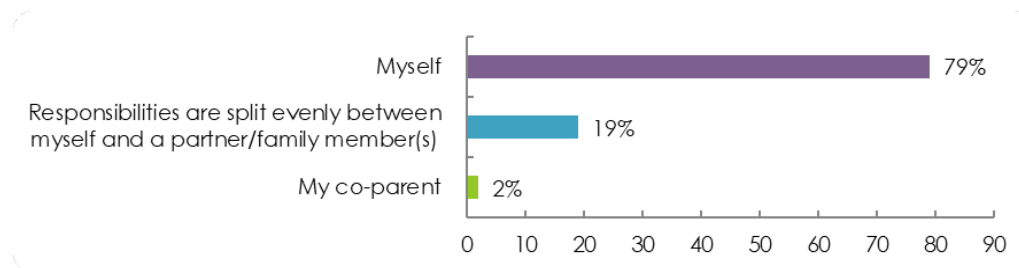
In the last month, on most days, how well do you think you are handling the demands of raising children? (n=53)



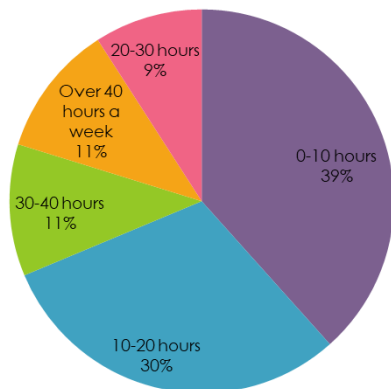
Do you have reliable access to respite care, which is when a professional caregiver gives you a temporary break (as short as a few hours) from primary caregiving responsibilities? (n=53)



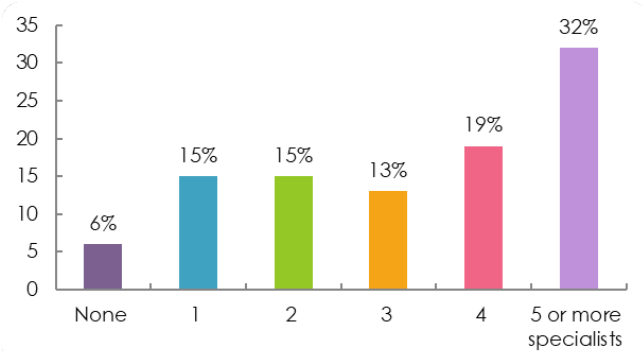
Who would you say takes on most of the responsibilities related to the care of your child(ren) with a chronic physical health condition(s)? (n=53)



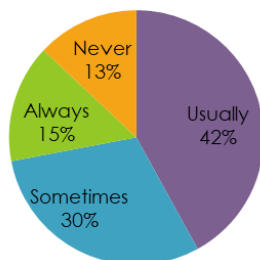
On average, how many hours a week do you spend providing care related to the medical needs of your child(ren) with a chronic physical health condition(s)? (n=53)



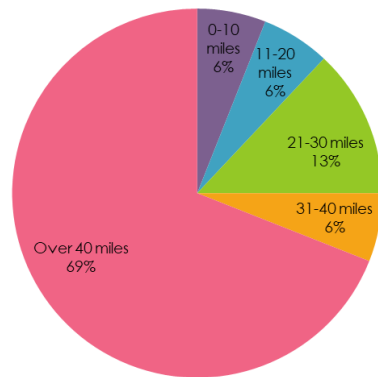
How many specialists has your child(ren) with a chronic physical health condition(s) seen in the last 12 months? (n=53)



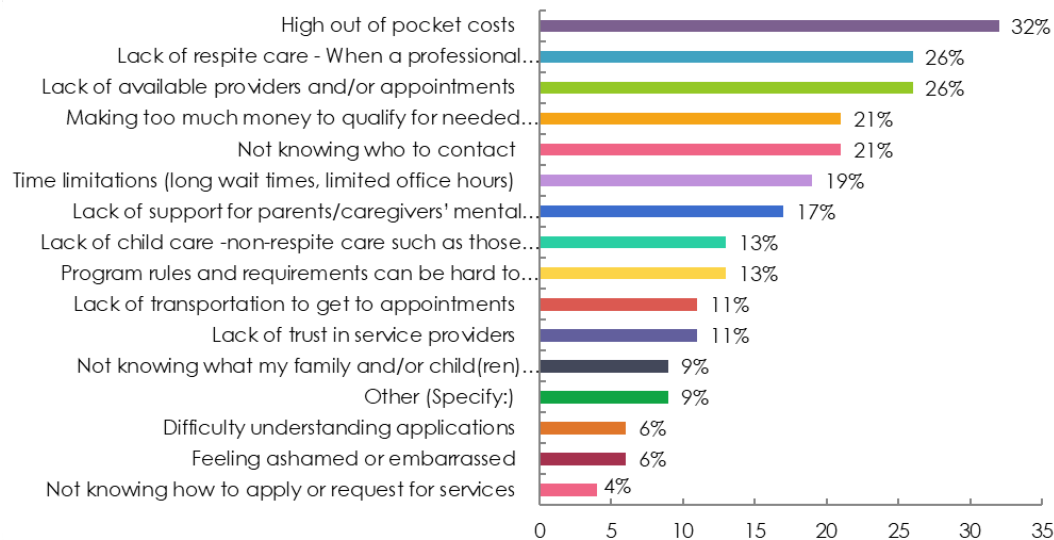
In the last 12 months, how often did you get appointments for your child(ren) with a chronic physical health condition(s) to see a specialist as soon as they needed? (n=53)



In the last 12 months, what is the average distance from your home that you have had to travel to get your child(ren) with a chronic physical health condition(s) to a needed service or appointment? (n=52)



What have been your family's top barriers in getting the services and supports your family needs? (Choose up to 3) (n=47)



Other (Specify:)

As specialist is at MGH. And lack of ortho in local area.

Insurance! Pre-auth and denials.

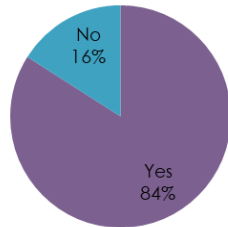
Lack of support from courts. If both parents have shared custody and one doesn't believe in getting the child help needed and the courts don't care then your child goes without. There needs to be help for parents that need help for their child.

Time management with 4 kids, and changing endocrinologist

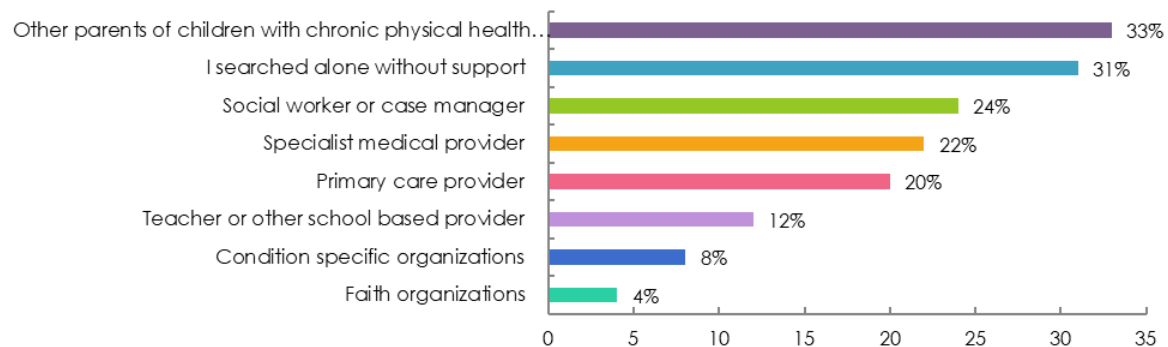
Let us know if you have you looked for any of the programs or other supports listed below to help your family in the care of your child(ren) with a chronic health condition(s)? (n=51)

	Got the support needed, and it was enough.	Got some support, but it wasn't enough.	Looked for supports for this concern and didn't get the help needed.	Did not look for supports for this concern.
	Count	Count	Count	Count
Care coordination/navigation	9	9	10	21
Income assistance	5	9	9	27
In-home nursing services	3	1	5	39
Child care	4	4	10	31
Respite care	1	4	13	30
School Based Services	20	8	11	9
Subsidized housing	3	2	5	40
Food support	8	7	9	27
Partners in Health	25	2	9	14
Behavioral health services for myself or another family member	10	8	9	21
Behavioral health services for my child	11	7	13	16
Services in a language other than English	1	0	0	46
Early intervention services	7	4	3	34
Health insurance	25	8	4	12
Disability-related legal assistance	2	3	8	34
NH 211	4	0	3	39

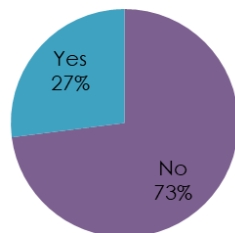
Survey Respondents' Aware of the Partners in Health Program? (n=51)



Who helped you in your search for services and supports for your family? (Select all that apply) (n=49)



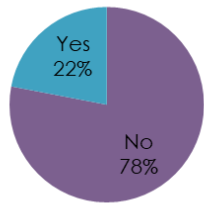
If your child(ren) received care during the past 12 months, did they receive family-centered care? (n=48)



How often did your family feel partnered in shared decision-making for your child(ren)'s health? (n=51)



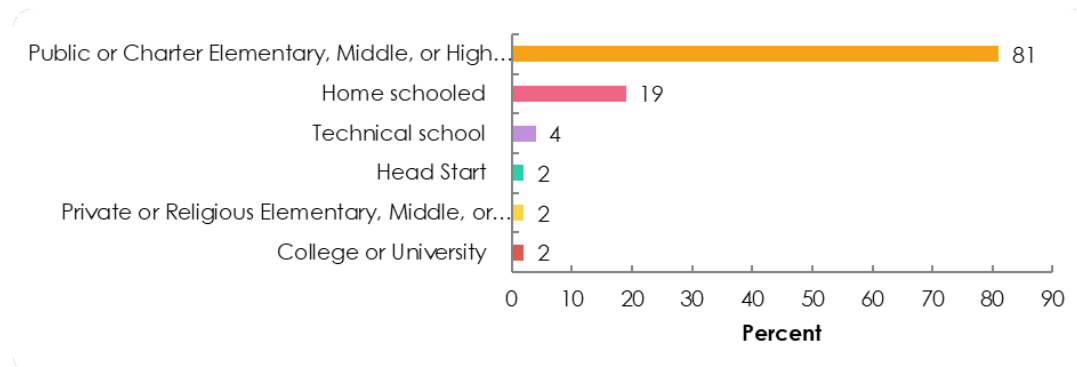
If your child(ren) with chronic physical health condition(s) are aged 14 and older, did they receive services needed for transition to adult health care? (n=23)



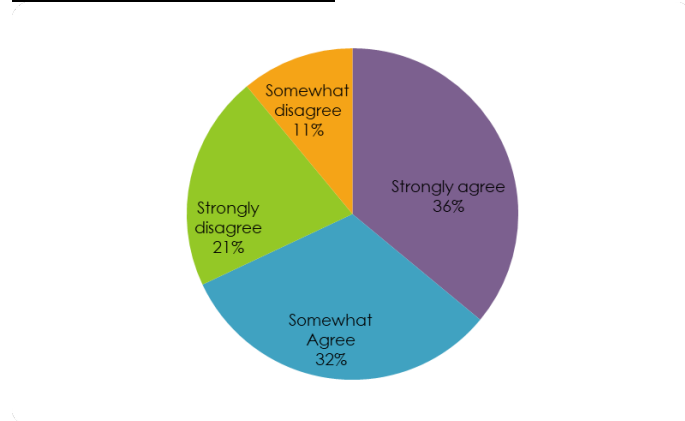
Please rate your level of agreement with the following statements.

	Strongly Disagree	Disagree	Agree	Strongly Agree
	Count	Count	Count	Count
My child's chronic physical health condition(s) is/are well managed.	2	8	23	15
Our family feels supported by our community.	6	13	21	10
My family and child are getting the help we need.	3	20	14	11
Our family has reliable child care.	8	12	11	6
Our family has access to respite care when we need it.	13	15	7	2
We have safe, stable housing.	3	4	11	32
We have enough money to pay for basic needs.	4	11	14	20
We have enough food to eat.	2	5	17	25
We have reliable transportation to get where we need to be.	3	5	16	26
I'm able to figure out what types of supports that work for my family.	1	8	23	13

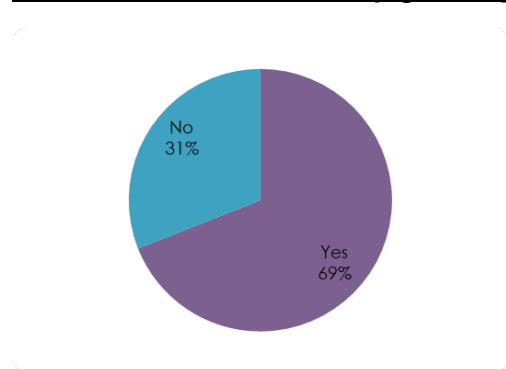
If your child(ren) with chronic physical health conditions are aged 3 and older, what sort of educational setting do they learn in? (Select all that apply) (n=48)



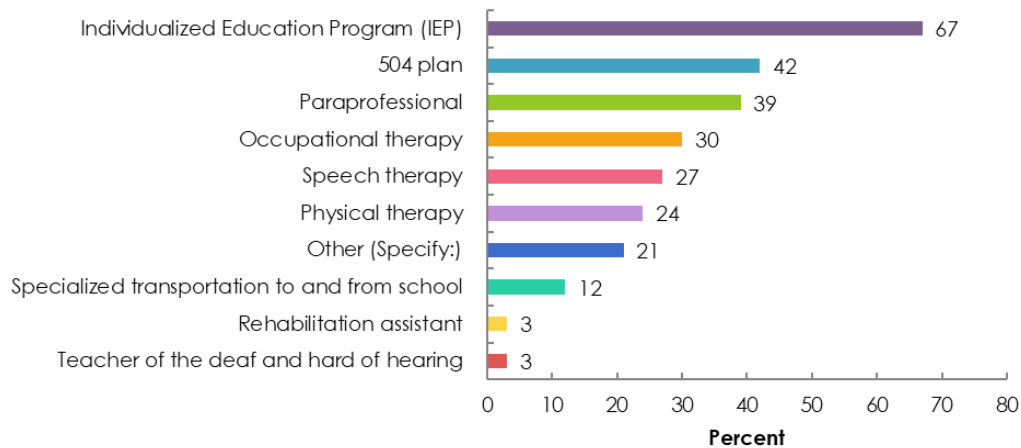
Please rate your agreement with the following statement: My child(ren)'s chronic physical health condition(s) greatly affected our decision on where they would receive their education. (n=47)



Does your child(ren) with a chronic health condition(s) receive additional supports and services at the school they go to? (n=48)



If yes, please specify which services. (Select all that apply)(n=33)



Other (Specify:)

1:1 nursing

Extended school year. School counseling.

Homebound education tutor

Physical supports as needed.

Rec tx, assistive technology

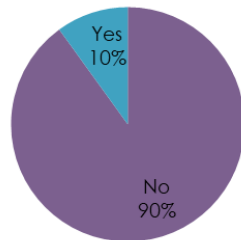
School counselor and class help via IEP

Vision specialists and a para with him at all times due to his vision, but there have been cases where he was left alone and got hurt and school covered it up!

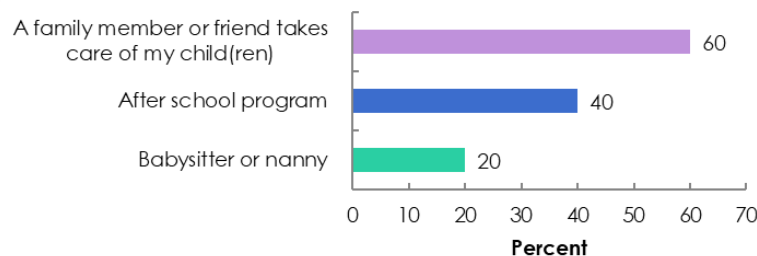
Please share your agreement with the following statements. My _____ offers enough supports and accommodations to help my family manage my child(ren)'s chronic physical health condition(s). (n=48)

	Strongly Disagree	Disagree	Agree	Strongly Agree
Count	Count	Count	Count	Count
Child(ren)'s school	6	10	19	12
Child(ren)'s teacher	3	9	20	12
Child(ren)'s school-based services	5	9	21	6

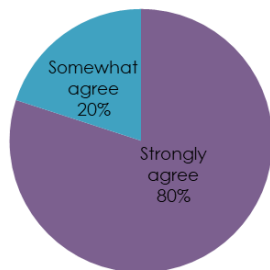
Does your child(ren) receive child care (non-respite care such as those offered by a babysitter, after school child care, or child care center) by someone or a program outside of your home, other than you or another guardian?(n=49)



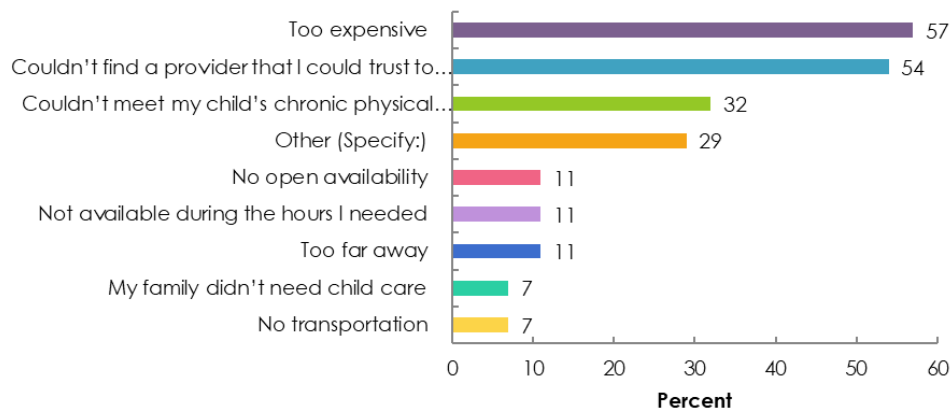
If yes, what type of child care or early learning program does your child(ren) go to right now? (Select all that apply). (n=5)



Please rate your agreement with the following statement: My child(ren)'s chronic physical health condition(s) greatly affected our decision on where they would receive child care.(n=5)



What affected your decision? (Select all that apply) (n=28)



Other (Specify:)

Asked for this but never gotten any help.

Due to trauma she's experienced, there are very few people she feels comfortable being left with.

My children were sick far too often from their disorder that necessitated me finding ways to work from home for added income. I was not hireable when my kids were IV infusion 80+ days per year and home to recover many more days than that. They have always done a form of remote schooling due to absences. Working for myself from home allowed me the flexibility needed

No babysitter

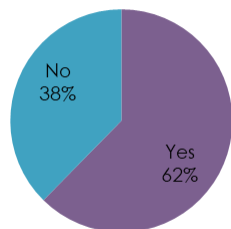
We have a nanny who cares for our child in our home. We explored private daycare options when he was little but we were told that we would have to send him with a para (defeating the purpose of sending him to daycare).

after school program rarer for teens, don't have to accommodate and developmentally growing out of "babysitter" stage but cannot be left alone

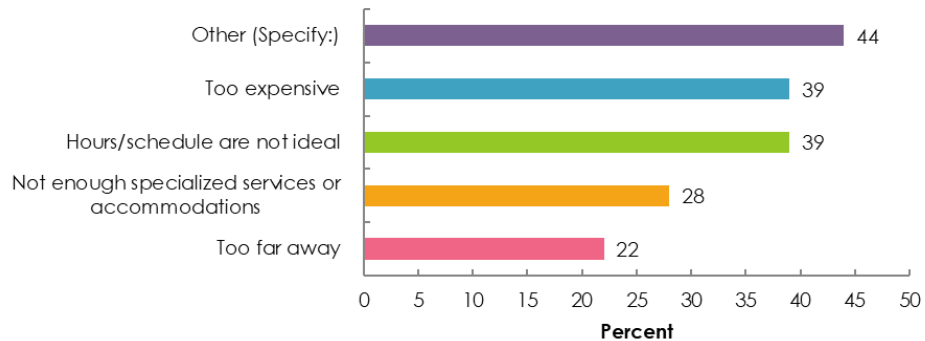
child is old enough to stay home

too much risk during pandemic

Do you feel that your current child care situation meets your family's needs? (n=48)



If no, why not? (Select all that apply) (n=18)



Other (Specify:)

DSP's are difficult to find and area agency offers little assistance

Due to trauma she's experienced, there are very few people she feels comfortable being left with.

Lack of understanding of my child's health care needs

My husband and I are exhausted

No one is available

Not safe without skilled staff

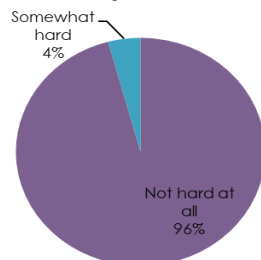
Unavailable

unable to work while child is in Homebound Education

In what language would you prefer to get services for your child or children with chronic physical health conditions? (n=46)



How hard is it for your child(ren) with a chronic health condition(s) to get health care services in their preferred language? (n=46)



Please tell us about your most recent experience related to services and supports for your family/child with chronic physical health conditions by sharing your agreement with the following statements. My family...(n=46)

	Strongly Disagree	Disagree	Agree	Strongly Agree	Don't know/Prefer not to say
	Count	Count	Count	Count	Count
Was treated with respect.	3	2	20	19	2
Felt that cultural and/or religious beliefs were respected.	0	3	18	15	10
Felt that staff cared.	4	4	23	13	2
Was offered an interpreter and materials in a different language as needed.	0	0	7	6	33
Got help with any physical limitations (Example: wheelchair accessibility, hard of hearing, etc.).	2	7	12	12	13
Got help with any learning needs (Example: used visual and verbal aids to teach).	3	8	10	10	15

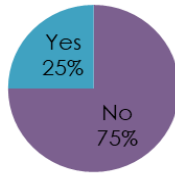
Young Adult Survey Respondents

Survey Respondents' Chronic Physical Health Condition(s) (n=7)

Chronic physical health conditions:	Count*
Asthma	3
Epilepsy	2
Blood related conditions	1
Congenital heart conditions	1
Autoimmune conditions	1
Cystic Fibrosis	1
Other condition(s) (e.g., hearing impairment, connective tissue disorder)	2

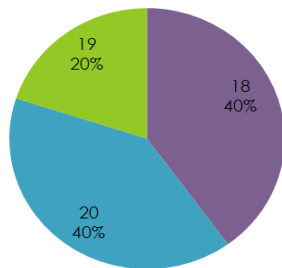
*Total exceeds response n of 7 because this survey item allowed respondents to select multiple chronic conditions

Survey Respondents Eligible for or Receiving Area Agency Services (n=7)²



Value	Percent	Count
No	75%	5
Yes	25%	2
Total:		7

Survey Respondents' Ages (n=5)

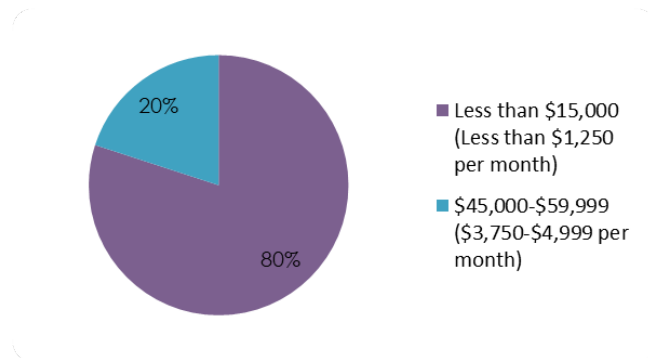


Survey Respondents' Town of Residence (n=5)

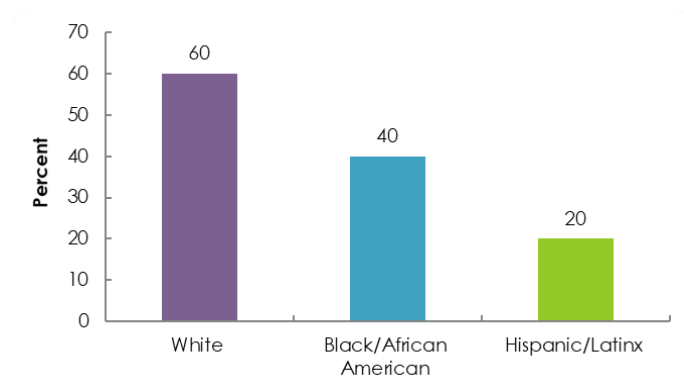
Value	Percent	Count	County
Keene	20%	1	Cheshire
Laconia	20%	1	Belknap
Manchester	20%	1	Hillsborough
Nashua	20%	1	Hillsborough
Pelham	20%	1	Hillsborough
Total:		5	

² This survey item was initially included as a screening question. In reviewing survey responses, the team determined that respondents experienced confusion around the meaning of 'area agency services', confusing it with Partners in Health services. JSI/CHI reviewed this survey item's data and compared it with responses to the survey item about the respondent's chronic condition(s). Survey responses that included a report of a developmental condition were removed from the dataset. Two survey responses met the inclusion criteria.

How much money did you or your family receive from all sources in 2021? Please include income from paid jobs, alimony/child support, insurance benefits, etc. (n=5)



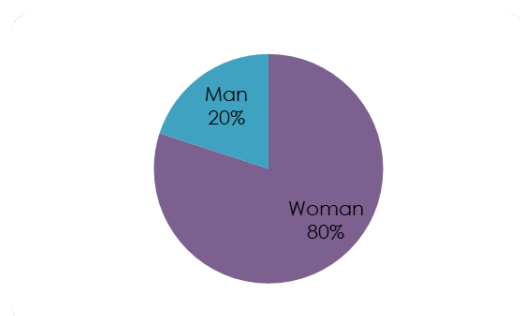
Survey Respondents' Ethnic or Racial Group(s) (n=5)



Value	Percent	Count
White	60%	3
Black/African American	40%	2
Hispanic/Latinx	20%	1

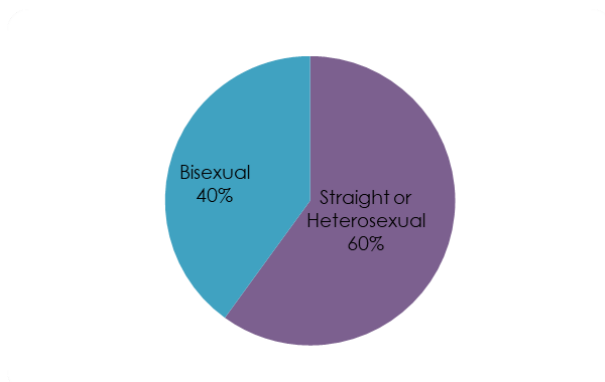
*Total exceeds response n of 5 because this survey item allowed respondents to select multiple chronic conditions

Survey Respondents' Current Gender (n=5)



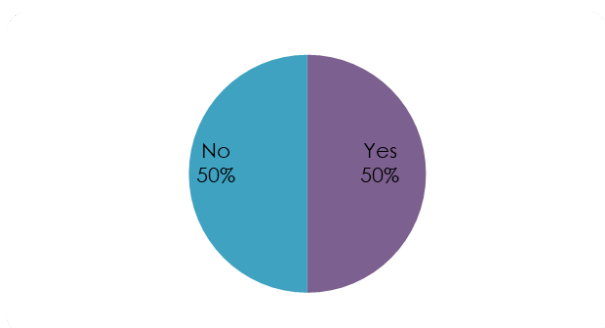
Value	Percent	Count
Woman	80%	4
Man	20%	1
	Total:	5

Survey Respondents' Sexual Orientation (n=5)



Value	Percent	Count
Straight or Heterosexual	60%	3
Bisexual	40%	2
	Total:	5

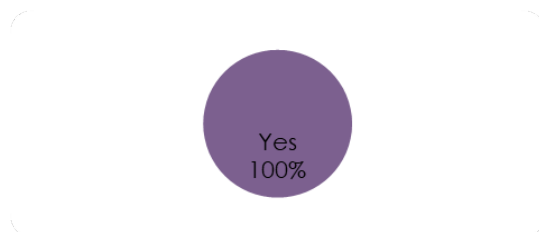
Do you feel your home's physical environment meets the needs of your chronic physical health condition(s)? (n=2)



If no, what kind of changes do you feel your home needs? (Select all that apply) (n=1)

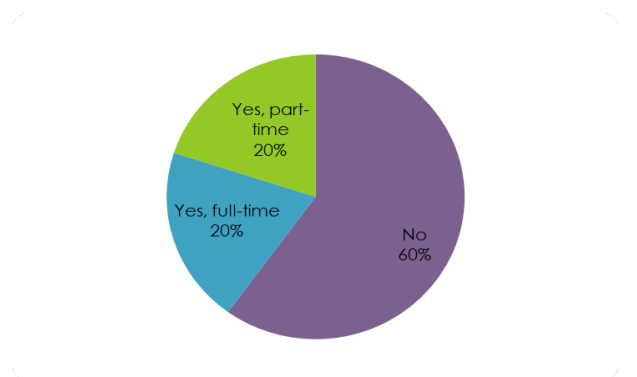
Value	Percent	Count
Low pile carpet	100%	1
Lower shelves and cabinets	100%	1
Air filters	100%	1

If no, is it because you needed financial support to make these changes but were unable to get it? (n=1)

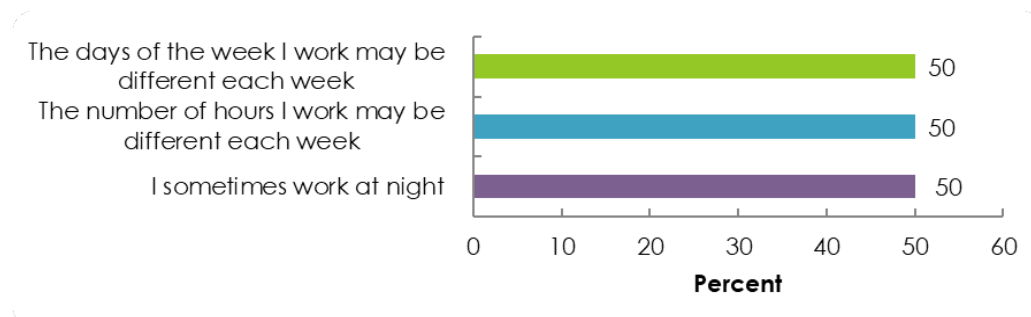


Value	Percent	Count
Yes	100%	1

Do you have a paid job? (n=5)



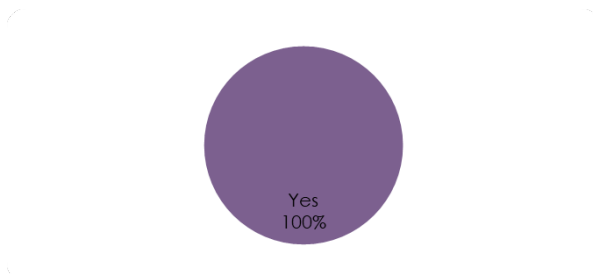
Which of the following applies to your current paid job? (Select all that apply) (n=2)



Due to your chronic physical health condition(s), have you ever had to do any of the following? (Select all that apply and for the ones you select, specify if the change was temporary or permanent) (n=5)

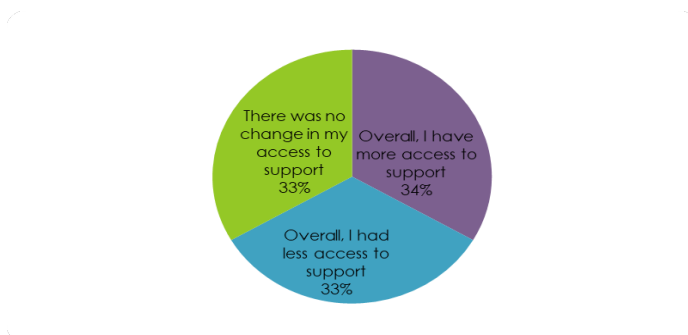
	Temporary	Permanent	Have not had to do any of these
	Counts	Counts	Counts
Take leave without pay	2	0	3
Change from full time to part time	0	1	4
Stop working	2	0	3
Change the days or time of day you work	2	1	2
Total	6	2	12
% of Total	30%	10%	60%

Did these changes result in reduced employment benefits such as health insurance, dental insurance, and paid time off? (n=3)

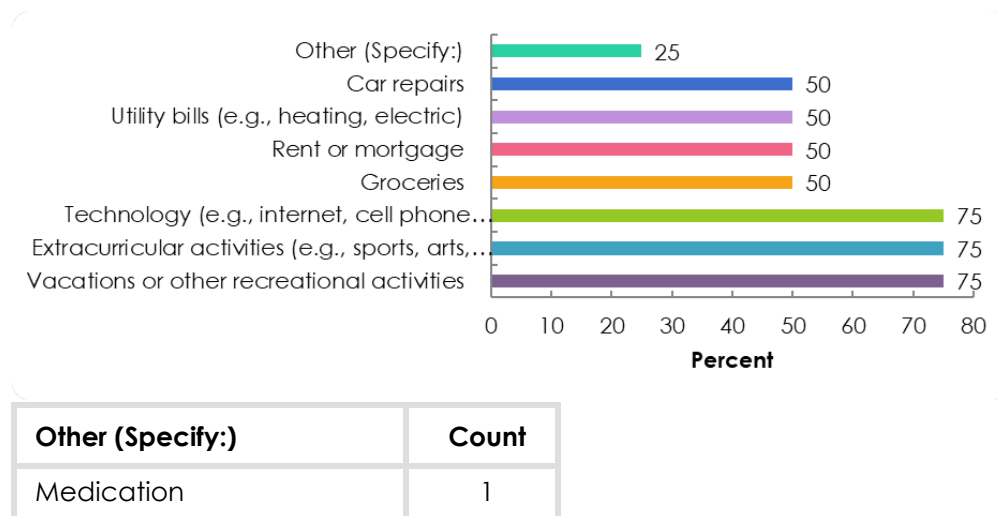


Value	Percent	Count
Yes	100%	3

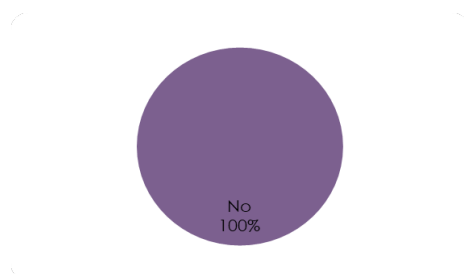
How did these changes to your benefits affect your ability to access any other kinds of supportive programs or resources (e.g., charitable organizations, diagnosis specific associations, WIC, housing subsidy, Medicaid, etc.)? (n=3)



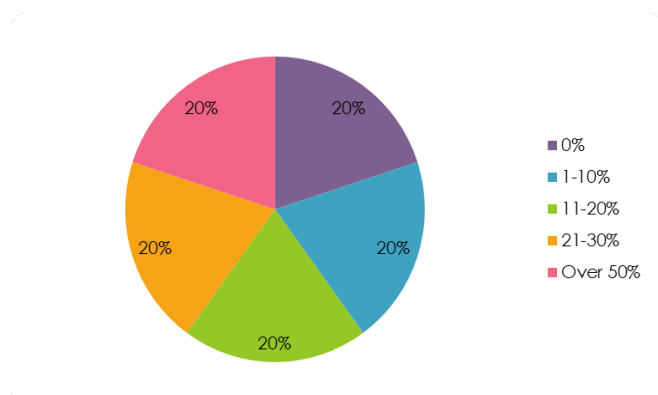
What kinds of items/services have you, at times, had a hard time paying for or had not been able to pay for at all due to the costs involved in caring for your chronic physical health condition(s)? (Select all that apply) (n=4)



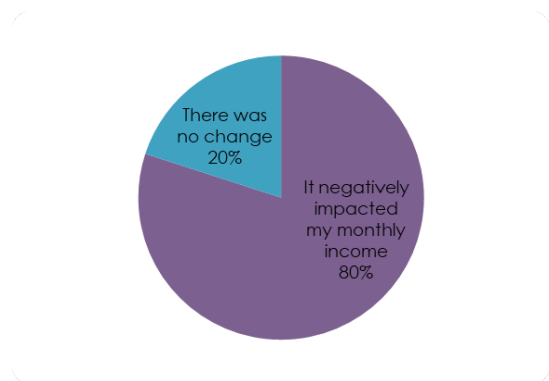
Have you ever gotten financial support for needed medical expenses or other essentials through a crowdsourcing website like GoFundMe? (n=5)



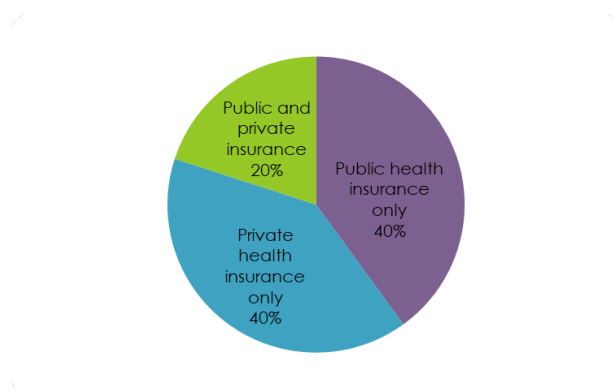
On average, in a month, what percentage of your household income are you spending to cover the cost of managing your chronic physical health condition(s)? Examples include: co-pays, prescription and over-the-counter medications, home services, specialized transportation, educational supports, therapies, etc. (n=5)



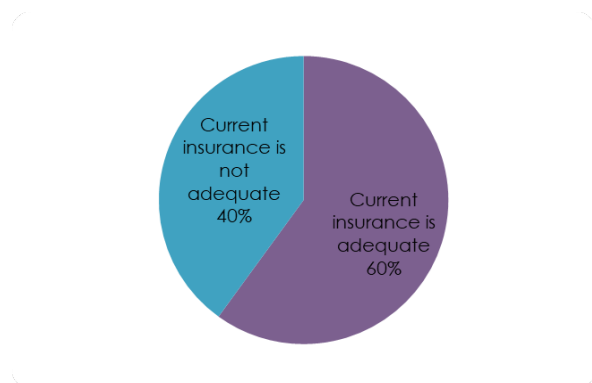
How has COVID-19 affected your income? (n=5)



What type of health insurance coverage, if any, do you have at the time of the survey? (n=5)



Does your current health insurance offer benefits or cover services that meet your needs? (n=5)

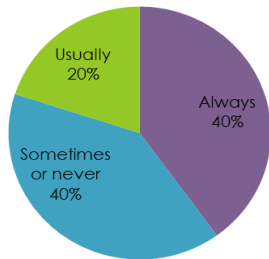


If no, list types of expenses that are NOT covered by insurance. (n=1)

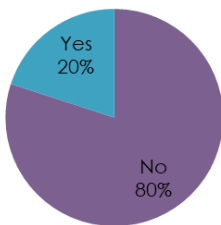
Response:

Certain specialists and treatment

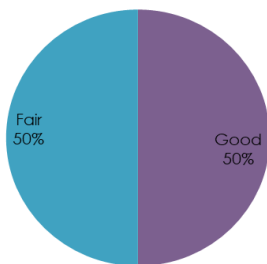
Thinking specifically about your mental or behavioral health needs, how often does your health insurance offer benefits or cover services that meet these needs? (n=5)



During the past 12 months, have you avoided changing jobs because of concerns about maintaining health insurance for your chronic physical health condition(s)? (n=5)



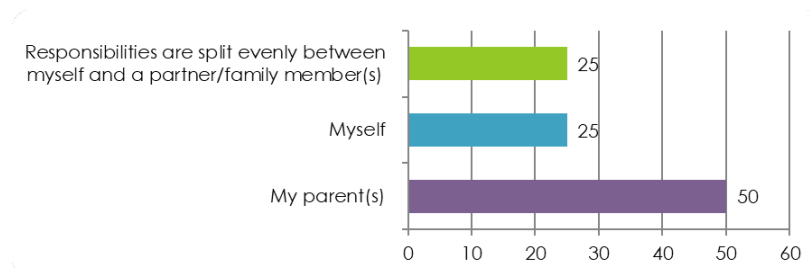
How would you rate your physical health status in general? (n=4)



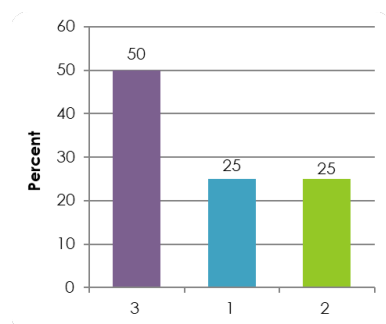
How would you rate your mental and emotional health status? (n=4)



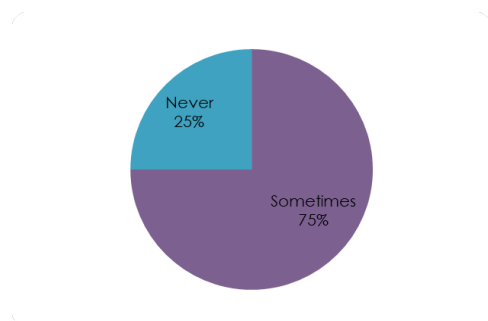
Who would you say takes on most of the responsibilities related to the care of your chronic physical health condition(s) (e.g., scheduling healthcare appointments)? (n=4)



How many specialists have you seen in the last 12 months? (n=4)



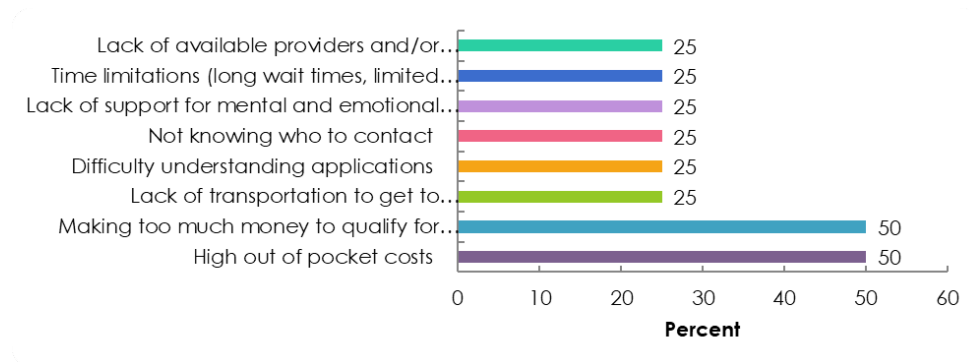
In the last 12 months, how often did you get appointments to see a specialist as soon as you needed? (n=4)



In the last 12 months, what is the average distance from your home that you have had to travel to get to a needed service or appointment? (n=4)

Value	Percent	Count
11-20 miles	50%	2
31-40 miles	50%	2
Total:		4

**What have been your top barriers in getting the services and supports you need?
(Choose up to 3) (n=4)**



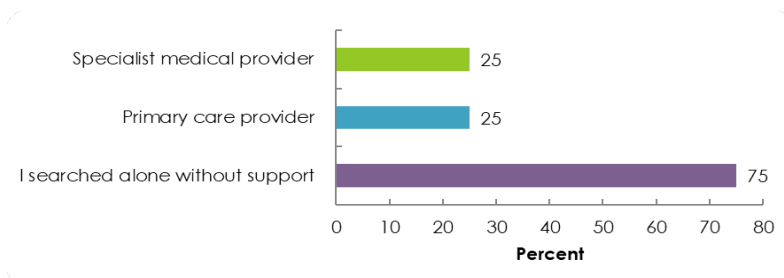
**Have you looked for programs or other supports in your community to help you with
your chronic health condition(s)? (n=4)**

	I got the support I needed, and it was enough.	I got some support, but it wasn't enough.	I looked for supports for this concern and didn't get the help I needed.	I did not look for supports for this concern.
	Count	Count	Count	Count
Care coordination/navigation	0	1	1	2
Income assistance	0	2	1	1
In-home nursing services	0	0	1	3
Child care	0	0	0	4
School-Based Services	0	0	2	2
Subsidized housing	0	0	2	2
Food support	0	1	1	2
Partners in Health	1	1	1	1
Behavioral health services	0	0	3	1
Services in a language other than English	0	0	0	4
Early intervention services	0	0	0	4
Health insurance	1	1	1	1
Disability-related legal assistance	0	1	0	3
NH 211	0	0	0	4

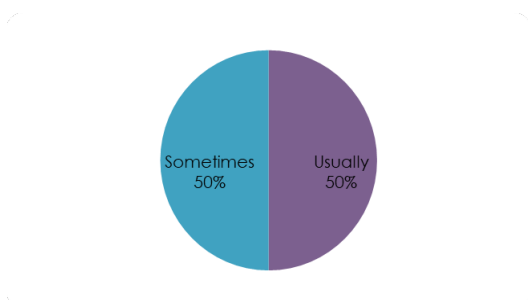
Are you aware of the Partners in Health program? (n=4)

Value	Percent	Count
Yes	100%	4

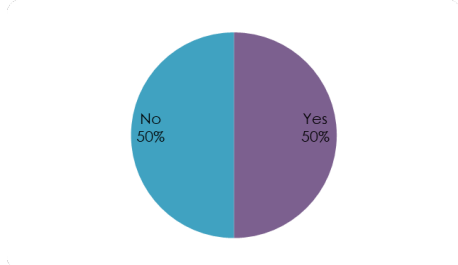
Who helped you in your search for services and supports for your chronic health condition(s)? (Select all that apply) (n=4)



How often do you feel partnered in shared decision-making for your health? (n=4)



Have you received the services needed for transition to adult health care? (n=4)



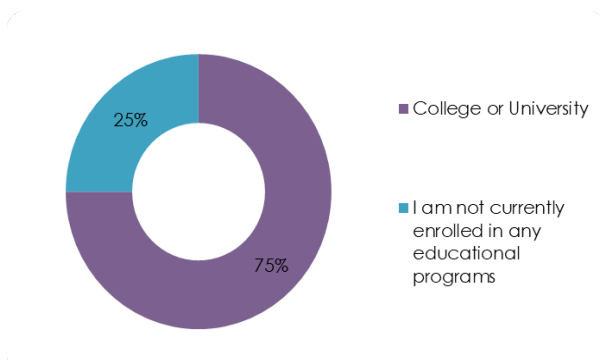
If no, what services would have been helpful for transitioning to adult health care? (n=2)

Responses:
Any help other than parent- they can only do so much and also don't know the process
Financial

Please rate your level of agreement with the following statements. (n=4)

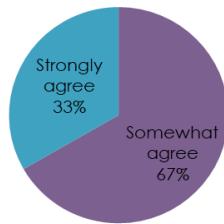
	Strongly Disagree	Disagree	Agree	Strongly Agree	Don't Know/Prefer Not to Say
	Count	Count	Count	Count	Count
My chronic physical health condition(s) is well managed.	0	1	2	0	1
I feel supported by my community.	0	3	1	0	0
I am receiving the help I need.	0	3	1	0	0
I have safe, stable housing.	0	0	2	2	0
I have enough money to pay for basic needs.	0	2	1	0	1
I have enough food to eat.	0	0	4	0	0
I have reliable transportation to get where I need to be.	0	0	4	0	0
I'm able to figure out what types of supports that work for me.	0	3	1	0	0

What sort of educational setting do you learn in? (Select all that apply) (n=4)



Value	Percent	Count
College or University	75%	3
I am not currently enrolled in any educational programs	25%	1

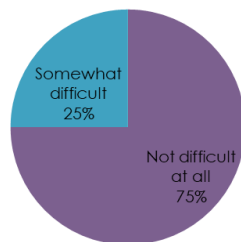
Please rate your agreement with the following statement: My chronic physical health condition(s) greatly affected my decision on where I receive my education. (n=3)



In what language(s) would you prefer to get services related to your chronic physical health condition(s) (n=4)

Value	Percent	Count
English	100%	4

How difficult is it for you to get health care services in your preferred language? (n=4)



Please tell us about your most recent experience related to services and supports for your chronic physical health conditions by sharing your agreement with the following statements. I... (n=4)

	Strongly Disagree	Disagree	Agree	Strongly Agree	Don't know/Prefer not to say
	Count	Count	Count	Count	Count
was treated with respect.	0	0	3	1	0
felt that cultural and/or religious beliefs were respected.	0	0	3	0	1
felt that staff cared.	0	1	3	0	0

was offered an interpreter and materials in a different language as needed.	0	0	2	0	2
received help with any physical limitations (example: wheelchair accessibility, hard of hearing, etc.).	0	0	2	0	2
received help with any learning needs (example: used visual and verbal aids to teach).	0	1	1	0	2

Appendix B: Key Informant Interview Questions

1. Please describe how you interact with families of children and/or young adults with chronic physical health conditions.
2. We would like to hear about the resiliency and strengths of the families you serve. What do you admire about the families you support?
3. In your opinion, what does the current system of services and support for these families do well?
4. What do you think are the top barriers for families with children with chronic physical health conditions in getting the services and supports they need?
5. What are the unmet needs of these families? In other words, where is the current system of services and support lacking?
6. What kind of families do you think have the greatest challenges in getting services and supports?
 - a. Family type?
 - b. Condition specific?
 - c. Communities?
7. Thinking of the family or young adult as a whole, what are some of the challenges you see these families face? (prompts: behavioral health, financial, family dynamics, etc.)
 - a. How do you change your approach to services knowing the particular barriers a family faces? (For example: expensive prescription medications, time/travel restrictions, language barriers, etc.)
8. From a provider perspective, tell us about what you need to better meet the needs of these families?
 - a. What about workforce or infrastructure issues?
9. What is one actionable change that you feel could reasonably be made in the next year that would have a positive impact for families?

For Healthcare Providers

1. How would you say your interaction with the child differs from your interactions with caregivers/parents?
2. How do your interactions change as the child ages into adolescence and adulthood?
3. What unmet needs are you seeing for youth with chronic physical health conditions?

Appendix C: Key Informant Interviews Qualitative Coding Scheme

Code	Description of Code
Impact of COVID-19 (Positive)	Descriptions of positive impacts of the COVID-19 pandemic, such as new funding sources available, access to/acceptance of work from home, or increase in access to telehealth.
Impact of COVID-19 (Negative)	Descriptions of negative impacts of the COVID-19 pandemic, such as limited home care services, rise in mental health needs, negative impacts on employment (e.g., lay offs), or staffing shortages.
School Supports and Services (Positive)	Positive supports and services provided by school systems, such as assistance with diagnosis or early detection, provision of case management services, or provision of referrals.
School Supports and Services (Negative)	Issues or challenges with the supports and services provided by school systems, such as lack of awareness of available services or lack of communication/poor communication of available services.
Resilience and Resourcefulness of Families	Descriptions of the strengths and resilience of caregivers/families, such as high level of advocacy for children, willingness to work within the system and with providers or professionals, or the ability of caregivers/families to learn and navigate systems.
Patient-Provider Relationships (Positive)	Positive patient-provider relationship descriptions, such as trust between families and providers, provision of patient-centered care, or providers serving as advocates for families.
Patient-Provider Relationships (Negative)	Negative patient-provider relationship descriptions, such as lack of family-friendly language, limited provision of patient-centered care, or providers' lack of understanding of caregiver knowledge of child(ren)'s diagnosis and/or healthcare needs.
Impact on Family Relationships	Impact of child(ren)'s chronic health condition on family relationships, such as the impact on other children in the family (e.g., lack of attention or care from caregivers), burden of providing childcare or medical care for sibling(s), or strained relationships among siblings.
Impact on Caregiver	Impact of child(ren)'s chronic health condition on their caregiver(s), such as impact on the mental health of caregivers (e.g., guilt, stress), high demand of full-time caregiving (e.g., caregiver burnout), or impact on relationships (e.g., divorce).
Strengths of Current Services and Support Systems	Descriptions of the strengths of the current services and support systems, such as access to care coordination services or access to primary care services (e.g., pediatricians).
Financial Impact on Families	Impact of child(ren)'s chronic health condition on family finances, such as insufficient insurance coverage, loss of income, or high out-of-pocket

	costs.
Family Barriers to Accessing Supports or Services/Unmet Needs	Family barriers to access supports or services for their child(ren) with chronic health conditions or family unmet needs. Examples include family structure (e.g., single parent, grandparent), caregiver's medical or mental health status (e.g., disability), geographic location (e.g., rurality), socioeconomic status, cultural or language barriers, family resistance or hesitation to seek services/supports, challenges understanding services/systems, or home modifications and access to accessible housing.
Challenges with the Healthcare System	Challenges with the healthcare system, such as high levels of staff turnover and inconsistency in treatment providers, lack of communication across systems, lack of available mental health services in state, lack of specialty care in state, low reimbursement rates, or insufficient insurance coverage.
Challenges with Other Systems (e.g., SNAP, WIC, case management)	Challenges with other systems in the state, such as eligibility criteria for services being too restrictive, poor communication around available resources and services, high burden of paperwork, lack of data sharing/interoperability across systems, or lack of funding for services.
Child Care, Respite Care, or Home Health Needs	Descriptions of child care, respite care, or home health, such as lack of accessible summer child care, lack of respite care availability, insufficient funding for respite care, or lack of home health services.
Transition Services for Young Adults	Transition planning supports for young adults, such as tools utilized to assess readiness, lack of availability of and connection to adult providers, or limited self-care skills training.

Appendix D: Focus Group Interview Questions

1. What brings your family joy? *[If adolescent/young adult living with a chronic physical health condition: What brings you joy?]*
2. What are some things in your home that make it harder or easier to live comfortably with a chronic physical health condition?
3. What kind of services and supports do you use that are helpful?
4. What kind of services and supports do you wish you had access to? Why don't you have access to them? (For example: doesn't exist, don't qualify, can't afford it, times available inconvenient, etc.)
5. How have you managed the financial impact of caring for your child? *[If adolescent/young adult living with a chronic physical health condition: How have you managed (if living by yourself) or your family has managed the financial impact of your care?]*
6. What are some things in your community that make your family feel more or less supported and included? *[If adolescent/young adult living with a chronic physical health condition: What are some things in your community that make you feel more or less supported and included?]*
 - a. Do you feel like your family can spend time in public spaces comfortably? *[If adolescent/young adult living with a chronic physical health condition: Do you feel like you can spend time in public spaces comfortably?]*
7. *[For family focus groups: What is your role in the care for your child?]*
 - a. *[Skip for adolescents. For those living with a partner]* How has your relationship been affected by your child's chronic physical health condition?
8. How has the quality time you spend as a family been affected by your chil(ren)'s chronic physical health condition? *[If adolescent/young adult living with a chronic physical health condition: How has the quality time you spend with your family been affected by your chronic physical health condition?]*
9. How are your other children impacted by your child's chronic health condition? *[If adolescent/young adult living with a chronic physical health condition: How has your family been impacted by your chronic health condition?]*
10. *[For families with children 13+]* How has your family's access to support changed as your child has aged? *[If adolescent/young adult living with a chronic physical health condition: How has your access to supports changed as you have aged?]*
11. If you could wave a magic wand, what would you change about the current supports and services offered to families of children with chronic physical health conditions?

Appendix E: Focus Groups Qualitative Coding Scheme

Code	Description of Code
Positives in Life	Descriptions of positive elements in families' lives, such as time spent with friends and families, travel, or recreation activities/hobbies.
Barriers Outside of the Home	Families' challenges with accessibility in the community or barriers outside of their home, such as playgrounds, shopping, recreation equipment, public restrooms, or public transportation.
Barriers Within the Home	Families' challenges with their home accessibility (e.g., stairs, bathrooms, kitchen) or modifications made to their home (e.g., rails, air purifiers).
Supports and Services (Positive)	Descriptions of supports and services that were helpful to families, such as support groups, support from family and friends, therapies (e.g., OT, PT, SLP), care management/coordination, state programs, non-profits, or faith-based organizations.
Supports and Services (Negative)	Issues, challenges, or gaps in supports or services, such as lack of specialty care in state, restrictive qualification criteria for services, lack of support groups or online communities for certain conditions, lack of vendors across the state, lack of mental health services and support for caregivers and children, lack of interoperability across systems, or high burden of paperwork.
School Supports and Services (Positive)	Positive supports and services provided by school systems, such as teachers who served as a good support or utilization of IEP and 504 plans,
School Supports and Services (Negative)	Issues or challenges with the supports and services provided by school systems, such as challenges with IEP and 504 plans being implemented, lack of awareness of supports/services needed, differences in school district policies and services, challenges with school transportation (e.g., wheelchair accessibility), or challenges of working with school nurses.
Child Care, Respite Care, or Home Health	Descriptions of child care, respite care, or home health, such as availability/use of child care, availability/use of summer camps, or availability of/funding for respite care.
Impact on Child with Chronic Condition(s)	Impact of living with chronic condition(s) on the child themselves, such as social impact (e.g., stigma, identity), developmental impact, or emotional/psychological impact.
Impact on Caregiver	Impact of child(ren)'s chronic health condition on their caregiver(s), such as emotional/psychological impact, high burden of caregiving (e.g., burnout) or advocacy, strain on partners' relationships (e.g., lack of quality time, stress), or unequal division of labor.

Impact on Family	Impact of child(ren)'s chronic health condition on family, such as impact on other children in the family (e.g., lack of attention from parents), emotional/psychological impact, or limitations on family quality time.
Family Barriers to Accessing Supports or Services/Unmet Needs	Family barriers to access supports or services for their child(ren) with chronic health conditions or family unmet needs, such as transportation issues, family structure (e.g., single parent, adoptive parents, grandparent), geographic location (e.g., rurality), or cultural or language barriers.
Impact of COVID-19	Descriptions of the impact of the COVID-19 pandemic, such as safety concerns, social isolation, lack of child care services, or lack of staffing for services.
Transition Services for Young Adults	Transition planning supports for young adults, such as availability of and connection to adult providers or transition to independent living.
Financial Impact on Families	Impact of child(ren)'s chronic health condition on family finances, such as challenges with health insurance coverage/reimbursement, high out-of-pocket costs (e.g., travel, home modifications), impact on employment status, need for multiple jobs, or lack of money for non-essentials (e.g., recreation).