Understanding the needs of foster parents of youth with special health care needs: Perceptions, barriers, and recommendations

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ARTICLE INFO

ABSTRACT

Introduction: Youth with special health care needs (SHCN) experience more placement disruptions in foster care than their typically developing peers. This study, conducted by a research-community partnership, used a mixed-methods approach to understand the needs and barriers of current, past, and prospective foster parents to provide care for youth with SHCN.

Methods: One hundred twenty-six participants completed a survey regarding their youth's care needs, anticipated and experienced barriers of concern when caring for youth with SHCN, support they believe should be provided at the beginning of placements, and information they believe would be helpful to know when deciding to foster a youth with SHCN.

Results: Current and past foster parents of youth with SHCN most commonly reported caring for youth with behavioral issues, developmental disabilities, and medical conditions requiring frequent monitoring and intervention. The biggest barriers reported by current and past foster parents were SHCN-specific training, transparency regarding youths' needs, and assistance finding providers. In contrast, prospective foster parents reported not receiving enough information about youths' specific needs and getting physical home modifications as the biggest anticipated barriers. Prospective foster parents reported they would like to receive clear information on youth's needs, care goals, and medical history to guide their decision to foster youth with SHCN.

Discussion: The findings from this study highlight that current, past, and prospective foster parents of youth with SHCN feel a critical need exists for additional capacity-building and resources for foster parents to be able to successfully care for youth with SHCN. Furthermore, prospective foster parents require tailored guidance and training to ensure they are fully prepared for the practical considerations to care for a youth with SHCN.

Conclusions: Foster parents who care for youth with SHCN require additional support to manage the complex medical and behavioral needs of the youth in their care, transparency on youth's medical history and care needs, and clarity on resources and services available. By identifying opportunities to better support, recruit, and prepare foster parents caring for youth with SHCN, the child welfare system can reduce gaps in wellbeing, promote placement stability, and improve outcomes for children and youth with SHCN.

1. Introduction

Youth with special health care needs (SHCN) are defined as youth "who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who require additional health services beyond those generally needed by typically developing youth" (McPherson et al., 1998). Youth with SHCN are more than three times as likely to experience maltreatment as compared to their typically developing peers (Jones et al., 2012; Sullivan & Knuston, 2000), and they often experience more severe injuries and maltreatment (Lightfoot et al., 2011; Sedlak et al., 2010). Further, 1 in 2 youth in the child welfare system have at least one SHCN (Bilaver et al., 2020; Helton et al., 2019; Ringeisen et al., 2008). Once youth are in the child welfare system, particularly in foster care, youth with SHCN experience increased length of time in foster care, lower rates of reunification with their biological parents (Rosenberg & Robinson, 2004; Slayter, 2016), worsened educational support and outcomes (Zetlin, 2009), and more unmet mental health needs (Haight et al., 2013). These disparities are compounded with higher rates of hospitalization, higher cost healthcare expenditures, and lower engagement in rehabilitative services such as

Early Intervention, special education services, and collaborative care (Bennett et al., 2020; Casanueva et al., 2020; Haight et al., 2013).

Given the vulnerable state of health and high rates of placement disruptions for youth in care with SHCN, foster parents of youth with SHCN must be equipped to support a variety of complex physical, social, and emotional needs. Ensuring foster parents have adequate support to meet each child's specialized needs is crucial to the development, wellbeing, and continuity of care for youth with SHCN (Duncan & Brooks-Gunn, 2000; Geenen & Powers, 2007) while also potentially reducing caregiver burnout and mental health symptoms (Macdonald & Kakavelakis, 2004; Whitt-Woosley et al., 2020). To ensure that foster parent supports are feasible and useful to foster parents in practice, efforts should prioritize foster parent needs and perspectives in the design and development of interventions to support youth with SHCN and their caregivers.

This study, conducted by a partnership of community and academic partners, emerged from community interest in understanding the experiences and barriers of fostering youth with SHCN as well as obstacles to recruiting new foster parents, given the high volume of youth with SHCN awaiting placements and the shortage of specialized foster parents (Esaki et al., 2012; U.S. Department of Health and Human Services, Administration on Children, Youth and Families, Children's Bureau, 2022). Thus, this study sought to survey current, past, and prospective foster parents of youth with SHCN to understand the needs and barriers they experienced – or anticipate experiencing – in caring for youth in care with SHCN. Additionally, this study sought to elicit participant feedback on information and supports needed to optimally support foster parents in caring for youth with SHCN. These findings seek to inform future capacity-building opportunities to better support, recruit, and prepare foster parents caring for youth with SHCN.

2. Methods

2.1. Procedure

This work was co-led by a group of child welfare researchers and a non-profit community agency focused on placement stability and foster parent support. The community partner provides direct support to foster families of youth with SHCN by offering licensing support, recruiting foster parents for traditional, specialized, and emergency foster care, and providing SHCN-specific training and support to foster parents. Further, the community partner aims to reduce the siloed nature of child welfare agencies by maintaining a statewide database of licensed families across Illinois agencies, improving the likelihood of identifying a placement for youth in care.

Through its direct work with this population, the community partner observed that finding placements for youth with SHCN had become a significant challenge. Thus, the academic and community partners sought to identify the needs and barriers experienced by current and past foster parents of youth with SHCN while also identifying prospective foster parents' anticipated barriers and concerns that impact their willingness to accept a placement. This study was reviewed and deemed exempt by the university partner's Institutional Review Board and was approved by community partner leadership.

To explore the perceptions and barriers experienced by this population, the research group iteratively co-designed a mixed-methods survey for distribution to current, past, and prospective foster parents in Illinois. Initial questions were guided by foster parent concerns reported to the community agency, as well as concerns they directly encountered when working with placements. Question themes were also informed by findings from a previous pilot survey conducted with specialized foster parents and caseworkers at the Illinois Department of Children and Family Services (DCFS). Community partner staff then provided feedback and further refined the survey questions to inform placement supports needed for prospective specialized foster parents.

The final survey was disseminated electronically by the community partner to their foster parent network via email, newsletters, webinars, and social media (e.g., Facebook and Instagram groups) from April 26, 2022 to June 3, 2022. Since the community partner is involved throughout Illinois and has a broad reach across agencies, recruiting participants through the community partner aimed to capture diverse experiences and perspectives across agencies in the state.

Inclusion criteria for survey participation were 1) living in Illinois at the time of survey completion; 2) feeling comfortable conducting the survey in English; and 3) currently, previously, or having interest in fostering youth with SHCN. To complete the survey, interested participants first completed a 7-question eligibility screen, followed by a 15–20-minute survey. Participants were not compensated for survey completion due to resource limitations. Current and past foster parents were asked about their experiences and barriers to successfully caring for youth with SHCN, while prospective foster parents were asked about anticipated care challenges. All respondents were asked about recommendations to improve support for foster parents and youth.

2.2. Survey measures

All eligible respondents provided sociodemographic information, in addition to whether or not they had prior experience caring for youth with SHCN professionally (e.g., work as a speech therapist for youth with SHCN) or personally (e.g., have a biological child with SHCN). Current and past foster parents were asked a total of 5 questions, including the care needs of their current or past youth in care and the severity of barriers to caring for youth with SHCN on a 5-point Likert scale ("Not a concern at all" to "Very much a concern"; response options 2 through 4 did not have a categorical label). A total of 17 barriers were listed and pre-determined by the research team based on prior experience and feedback from foster parents. Additionally, current and past foster parents had the opportunity to provide open-ended responses of other barriers to caring for youth they have encountered, support they would have liked to receive during these placements, and support they received that was helpful in maintaining placements.

Prospective foster parents were asked a total of 4 questions, including the type of care needs they would consider supporting, as well as how much of a concern they anticipated specific barriers being to foster a youth with SHCN on a 5-point Likert scale ("Not a concern at all" to "Very much a concern"; response options 2 through 4 did not have a categorical label). Based on coordination with the community partner, the research team chose to exclude three barriers from the prospective foster parent version of the survey due to their irrelevance to this group. These excluded barriers were considered to be overly specific and difficult to speculate about without actual fostering experience. Thus, a total of 14 barriers were listed and pre-determined by the research team. Prospective foster parents also described other concerns in open-ended responses regarding fostering a youth with SHCN and information that would be helpful to know when deciding to foster a youth with SHCN.

2.3. Analysis

Participants were grouped as current, past, or prospective foster parents based on their response to the question, "Have you ever fostered a child with complex medical needs and/or developmental disabilities?". Current foster parents include respondents who currently have a youth with SHCN under their care and past foster parents include those who fostered a youth with SHCN in the past, but currently have no youth under their care. Prospective foster parents include respondents who reported they are not currently a foster parent but are interested in becoming one.

Demographic comparisons for variables with continuous outcomes (e.g., age, number of household adults) were completed using t-tests for variables with two categories and one-way ANOVA tests for variables with 3 or more categories. Homogeneity of variance was confirmed for all comparisons.

To assess barriers, items ranked as a 4 or 5 were classified as a concern for that barrier. Then, categorical comparisons were conducted using Fisher's Exact Tests to assess the association between demographic factors and the number of respondents who indicated a barrier was a concern for them. Average barrier rating differences between current, past, and prospective foster parents were also assessed using one-way ANOVAs with Tukey's HSD (Honest Significant Difference) post-hoc tests. Differences in average ratings for those with lived experience (current and past foster parents) and prospective foster parents were assessed using two-way t-tests. Responses to open-ended questions were analyzed using thematic analysis based on recurring patterns and themes of responses, which were subsequently refined and categorized.

3. Results

3.1. Participants

The survey was accessed by 225 individuals, 206 completed the eligibility screen, and 126 completed the survey (80 respondents were

deemed ineligible). The final sample consisted of 40 (32 %) current foster parents of youth with SHCN, 42 (33 %) past foster parents, and 44 (35 %) prospective foster parents. Respondents were on average 44 years old (SD = 10; range = 25–68) and identified as White (60 %), not Hispanic/LatinX (59 %), as a cisgender woman (59 %) and having at least a bachelor's degree (50 %). Forty-two percent of respondents reported that two adults, including themselves, were available in the household to provide care to youth with SHCN, 19 % reported one adult, 7 % reported more than 2 adults, and 32 % were unreported. Twenty-nine percent of respondents had a traditional foster care license, 18 % had a specialized foster care license, and 25 % did not have a foster care license. Finally, 29 % of respondents reported having prior professional experience working with youth with SHCN, and 54 % reported having prior personal experience. Table 1 indicates demographic breakdown by groups.

No significant differences in age or the number of adults in the household were found between the three foster parent groups. Significant differences were observed in the number of household youth in care (F[2] = 11.4; p < 0.001), with prospective foster parents reporting fewer

Table 1
Participant demographic information.

	Current (n = 40)	Past (n = 42)	Prospective (n = 44)	p-value
Average Age (SD)	42.7 (8.4)	46.2 (9.9)	43.4 (12.6)	0.37
Race				<0.001
Black or African American	1 (2.5 %)	3 (7.1 %)	3 (6.8 %)	
Middle Eastern or North African	1 (2.5 %)	0 (0 %)	0 (0 %)	
White	33 (82.5 %)	29 (69.0 %)	13 (29.5 %)	
Multi-racial/Mixed Race	0 (0 %)	1 (2.4 %)	2 (4.5 %)	
Not Reported	5 (12.5 %)	9 (21.4 %)	26 (59.1 %)	
Hispanic/LatinX	3 (7.5 %)	3 (7.1 %)	2 (4.5 %)	<0.001
Gender				<0.001
Cisgender Man	2 (5.0 %)	1 (2.4 %)	1 (2.3 %)	
Cisgender Woman	32 (80.0 %)	26 (61.9 %)	16 (36.4 %)	
Non-binary/Gender Non-conforming	0 (0 %)	1 (2.4 %)	1 (2.3 %)	
Other/Not listed	0 (0 %)	1 (2.4 %)	0 (0 %)	
Not Reported	6 (15.0 %)	13 (31.0 %)	26 (59.1 %)	
Household Income				<0.001
Below $50,000	5 (12.5 %)	2 (4.8 %)	3 (6.8 %)	
$50,000-$99,999	16 (40.0 %)	15 (35.7 %)	6 (13.6 %)	
$100,000-$149,999	6 (15.0 %)	9 (21.4 %)	3 (6.8 %)	
$150,000 or Above	7 (17.5 %)	5 (11.9 %)	5 (11.4 %)	
Not Reported	6 (15.0 %)	11 (26.2 %)	27 (61.4 %)	
Household Highest Education Level				<0.001
High School or GED	0 (0 %)	3 (7.1 %)	0 (0 %)	
Some College	2 (5.0 %)	6 (14.3 %)	1 (2.3 %)	
Associate's Degree or Vocational Training	5 (12.5 %)	3 (7.1 %)	2 (4.5 %)	
Bachelor's Degree	10 (25.0 %)	4 (9.5 %)	5 (11.4 %)	
Master's Degree	12 (30.0 %)	12 (28.6 %)	8 (18.2 %)	
Advanced Degree (PhD, MD, JD, etc.)	5 (12.5 %)	5 (11.9 %)	2 (4.5 %)	
Not Reported	6 (15.0 %)	9 (21.4 %)	26 (59.1 %)	
Employment				<0.001
Unemployed	0 (0 %)	2 (4.8 %)	0 (0 %)	
Employed Part-time	6 (15.0 %)	8 (19.0 %)	2 (4.5 %)	
Employed Full-time	21 (52.5 %)	15 (35.7 %)	11 (25.0 %)	
Stay-at-home Caregiver	8 (20.0 %)	5 (11.9 %)	2 (4.5 %)	
Other	0 (0 %)	2 (4.8 %)	2 (4.5 %)	
Not Reported	5 (12.5 %)	10 (23.8 %)	27 (61.4 %)	
Household Adults Available for Care	2.0 (0.9)	1.67 (0.5)	2.1 (1.0)	0.12
Youth Under the Age of 18 in the Home	3.1 (1.6)	2.2 (1.6)	1.0 (1.5)	<0.001
License Type				0.48 *
No Foster Care license	0 (0 %)	1 (2.4 %)	30 (68.2 %)	
No Current License; in the Process of Getting a Traditional License	0 (0 %)	1 (2.4 %)	8 (18.2 %)	
No Current License; in the Process of Getting a Specialized License	0 (0 %)	0 (0 %)	2 (4.5 %)	
Traditional Foster Care License	21 (52.5 %)	15 (35.7 %)	0 (0 %)	
Specialized Foster Care License	11 (27.5 %)	12 (28.6 %)	0 (0 %)	
Specialized and Traditional Foster Care Licenses	7 (17.5 %)	10 (23.8 %)	0 (0 %)	
Previously Licensed, but no Current License	0 (0 %)	2 (4.8 %)	2 (4.5 %)	
Not Reported	1 (2.5 %)	1 (2.4 %)	2 (4.5 %)	
Professional SHCN Experience	16 (40.0 %)	13 (31.0 %)	7 (15.9 %)	<0.001
Personal SHCN Experience	24 (60.0 %)	31 (73.8 %)	13 (29.5 %)	<0.05

* Statistical significance of license type was only tested between current and past foster parents.

youth under their care. Significant differences were also observed in race, ethnicity, gender, education level, income, and employment status between the three groups (p < 0.001 for all variables), with higher rates of unreported responses among prospective foster parents. Significant differences were also observed in household income (p < 0.01), with current and past foster parents more likely to have a lower household income compared to prospective foster parents. Significant differences were observed in prior professional and personal experience caring for youth with SHCN, with current and past foster parents more likely to have prior professional experience, past foster parents more likely to have prior personal experience, and prospective foster parents more likely to have unreported responses. The statistical significance of license type was only tested between current and past foster parents, with no significant differences observed.

3.2. Current & past foster parents

Table 2 describes youth care needs that current and past foster parents reported having experience caring for. The most common care needs reported among current and past foster parents include behavioral issues, developmental disabilities, and complex medical conditions requiring frequent medical visits and medications.

Table 3 describes current and past foster parent ratings for level of concern for a variety of barriers to fostering youth with SHCN. Current foster parents most commonly reported delays in accessing services for youth and not knowing where to find services for youth, while past foster parents most commonly reported lack of support for managing youth's behaviors and lack of access to mental or behavioral support services for youth (including 24-hour crisis interventions).

Current foster parents (n = 24) re-emphasized in their open-ended responses that difficulty communicating with the youth's care team (n = 5; 21 %), and lack of agency support (n = 5; 21 %) posed barriers to successful placements of youth with SHCN. Additionally, participants

noted that slow response times for service consent from agencies (n = 2; 8 %) and limited access to appropriate amounts of services (n = 2; 8 %) hindered timely access to care. Some participants indicated that the delay in accessing and the limited amount of services had significant consequences - as one participant shared, during the six-month waitlist for a residential program, their youth in care had several aggressive episodes that put the foster parent, their children, and the youth in care in danger. However, "[the agency] only offered one hour of talk therapy a week for children who are severely traumatized and in need of significant intervention." (Participant #48).

Past foster parents (n = 20) emphasized a lack of agency support (n = 3; 15 %), insufficient insurance coverage and in-network providers (n = 3; 15 %), delays in processing referrals and requests (n = 2; 10 %), and difficulty accessing services (n = 2; 10 %). Participants also emphasized the challenge of finding appropriate respite care for medically fragile youth (n = 2; 10 %). As one participant stated, "These children [require] 24/7 care. Parents need breaks." (Participant #75).

Table 4 provides themes that current and past foster parents identified as support needed at the beginning of placements. Half of current foster parents (n = 14; 50 %) identified the need for improved communication, including transparency regarding prior history and interventions that were successful or unsuccessful in previous placements. Current foster parents (n = 12; 42 %) also reported the need for more wraparound support for foster families and youth with SHCN. Assistance finding available in-network services and providers was also emphasized by current foster parents (n = 10; 36 %) and past foster parents (n = 8; 36 %). One current foster parent noted that the time needed to learn the nuances of navigating the healthcare system may compromise their ability to fully meet the needs of their youth in care:

"Extra help finding specialists nearby, setting up appointment[s], getting medication orders and refills. All these tasks take an incredible amount of time and require many, and long, phone calls or waits on hold. This takes

Table 2
Youth care needs among current and past foster parents.

	Current (n = 40)	Past (n = 42)
Behavioral issues	29 (72.5 %)	33 (78.6 %)
Complex medical conditions requiring frequent medical visits and medications	18 (45.0 %)	22 (52.4 %)
Developmental disabilities	23 (57.5 %)	26 (61.9 %)
Non-ambulatory, wheelchair bound	3 (7.5 %)	8 (19.0 %)
Severe communication issues	8 (20.0 %)	14 (33.3 %)
Severe sensory issues	10 (25.0 %)	13 (31.0 %)
Technology dependent (e.g., tubes, ventilator, tracheostomy, etc.)	6 (15.0 %)	11 (26.2 %)
Other	5 (12.5 %)	4 (9.5 %)

Table 3
Percent of current and past foster parents reporting barriers as a problem or concern.

Barrier	Current (n = 40)	Past (n = 42)
Delays in accessing services for my youth	70 %	52 %
Not knowing where to find services for my youth	65 %	38 %
Lack of support for managing my youth's behaviors (e.g., aggressive behaviors)	63 %	55 %
Lack of access to mental or behavioral support resources for my youth (e.g., 24 h crisis interventions)	58 %	55 %
Lack of access to appropriate child care	55 %	48 %
Not having adequate respite support (short-term relief for caregivers)	55 %	52 %
Not having access to specialty doctors (e.g., few/none near me)	50 %	38 %
Not receiving enough information about what specific needs my youth has	45 %	48 %
Not receiving enough education or training about how to care for my youth	43 %	21 %
Lack of clear communication between providers (e.g., doctors, teachers, caseworkers)	38 %	40 %
Out of pocket costs	38 %	26 %
Difficulty getting equipment needed for my youth's condition	35 %	21 %
My personal mental and/or physical health	33 %	26 %
Difficulty finding nursing care	30 %	26 %
Difficulty getting physical modifications in/to my home (e.g., ramps)	23 %	17 %
Lack of reliable transportation	23 %	10 %
Lack of adaptive transportation (e.g., car that's been adapted for wheelchairs)	13 %	17 %

Table 4
Themes and sub-themes for support recommended by current & past foster parents.

What kind of support would you have liked to have at the beginning of the placement(s)?	Current (*n* = 28)	Past (*n* = 22)
Education and training	**5**	**3**
Additional education and training		
Information on how to contact people for different situations		
Holistic support and resources	**12**	**9**
Additional resources for youth yet to be specialized (financial, therapy)		
Adequate and appropriate mental health services and therapies		
Child care and respite care		
Connect with previous foster parents and/or provide mentors		
On-demand services for youth and foster parents		
Primary navigator to oversee entire case and coordinate all services for youth		
Support for entire foster family (e.g., family therapy, parenting classes)		
Transportation assistance		
Communication and transparency	**14**	**13**
Communication portal		
Faster processing times and responses		
Transparency on youth needs and behaviors		
Medical and health care support	**10**	**8**
Ensure nursing care is setup prior to hospital release		
Improved continuity of care		
Scheduling and medication refill assistance		
Stability and consistency in case workers		
Support finding available services, resources, and in-network providers		
Support from specialist case management teams with medical background		
Youth assessments in-between placements		

time away from caring for the child or getting other household tasks completed." (Participant #91)

Past foster parents similarly reported transparency on youth needs and behaviors prior to placement as their most frequent recommendation (n = 13; 59 %), including future medical appointments. One participant shared the importance of full disclosure of medical history, stating:

"I brought home a baby from a NICU, and no one told me he was scheduled for open heart surgery in 5 weeks." (Participant #27)

Table 5
Themes and sub-themes for support received by current & past foster parents.

What supports were helpful for you in maintaining this placement?	Current (*n* = 28)	Past (*n* = 18)
Agency support and resources	**14**	**7**
Child care and respite care		
Foster Parent Support Specialists		
Practical support for foster family		
Screening, Assessment, and Support Services (SASS)		
Support from caseworkers and agency		
Virtual support meetings		
Youth mentor		
Community and personal support	**18**	**5**
Community support systems (e.g., youth leaders, church, etc.)		
Love for the youth in care		
Other foster parents and parenting coaches		
Personal finances		
Personal support system (e.g., family, personal therapy, etc.)		
Prior knowledge, health literacy, and independent research		
Medical support and specialized designations	**12**	**6**
Communication with medical team via MyChart		
Early intervention		
Medicaid waiver programs		
Services offered outside of DCFS		
Specialized designation and approval of specialized services		
Support from medical/behavioral health team		
Supports were theoretically present, but not practically accessible	**1**	**3**
Support existed on paper, but did not come to fruition		

Table 5 describes themes regarding what supports were most helpful for current and past foster parents in maintaining a placement for a youth with SHCN. A significant portion of current foster parents reported support from the agency and caseworkers (n = 14; 50 %) and their community and personal support systems (e.g., family, other foster parents, personal therapy, etc.) (n = 18; 64 %) were essential during their fostering experience:

"Honestly, our friends and family stepped up. They provide respite for us and a safe space to feel all the feelings associated with fostering." (Participant #110)

Current foster parents also noted support from their youth's medical and behavioral health team were helpful to maintaining successful placements (n = 11; 39 %). Some respondents also stated their ability to provide financial support beyond their stipend enabled them to access additional services, including home care and therapies not covered by insurance (n = 3; 14 %).

Past foster parents emphasized that support, trust, and adequate communication from caseworkers were essential (n = 7; 39 %), as well as support from the youth's medical and behavioral health teams (n = 6; 33 %). Past foster parents also emphasized the importance of learning from others while fostering, either through a network with other foster parents (n = 2; 11 %) or by seeking services outside of DCFS, such as health care services at free health department clinics (n = 2; 11 %). Finally, one previous foster parent emphasized that some agency services are difficult to access, especially due to their location:

"The support I was offered looked good on paper but [was] not real… Located at the southern tip of IL - [there are] no supports, except on paper." (Participant #28)

3.3. Prospective foster parents

Fifty-nine percent of prospective foster parents reported that they are open to fostering youth with SHCN (n = 26). Table 6 describes youth care needs that prospective foster parents are open to caring for. Participants reported being most open to caring for youth with developmental disabilities, complex medical conditions that require frequent medical visits and medications, and behavioral issues. In contrast, prospective foster parents reported reluctance in fostering youth who are non-ambulatory or wheelchair-bound, youth with technology-

Table 6

Youth care needs prospective foster parents reported being open to care for.

	Prospective (n = 44)
Behavioral issues	11 (25.0 %)
Complex medical conditions requiring frequent medical visits and medications	16 (36.4 %)
Developmental disabilities	21 (47.7 %)
Non-ambulatory, wheelchair bound	5 (11.4 %)
Severe communication issues	9 (20.5 %)
Severe sensory issues	8 (18.2 %)
Technology dependent (e.g., tubes, ventilator, tracheostomy, etc.)	8 (18.2 %)
Other	5 (11.4 %)

dependent needs (e.g., tubes, ventilator, tracheostomy, etc.), who have severe sensory issues, and who have severe communication issues.

Table 7 describes how prospective foster parents rated how much of a concern various potential barriers are when considering fostering youth with SHCN. The most highly reported anticipated barriers include a lack of access to mental or behavioral services for youth, not receiving enough information about what specific needs their youth has, lack of adaptive transportation (e.g., car that's been adapted for wheelchairs), and not receiving enough education or training about how to care for their youth.

Of the 10 open-ended responses provided regarding other barriers of concern, 10 % of participants cited a lack of access to medical services and therapies (n = 1) and respite care (n = 1). Finally, concerns of maintaining their job (n = 1; 10 %), space in the home (n = 1; 10 %) and hesitation in fostering youth with aggressive behaviors (n = 1; 10 %) were also noted.

Of the 9 open-ended responses to the question regarding information that would be helpful to know when deciding to foster youth with SHCN, 56 % of participants emphasized clear information on youth's needs, care goals, and medical history (n = 5) and 22 % noted clear communication from the youth's medical team (n = 2). Eleven percent of participants also reported it would be helpful to receive information on who to contact at the agency for additional assistance (n = 1) and training available for foster parents (n = 1). Additionally, one participant noted that it would be helpful to know if they can opt into fostering youth based on health care needs they are already comfortable working with.

Table 7

Percent of prospective foster parents reporting barriers as an anticipated concern.

Barrier	Prospective (n = 44)
Lack of access to mental or behavioral support resources for my youth (e.g., 24 h crisis interventions)	34 %
Not receiving enough information about what specific needs my youth has	32 %
Not receiving enough education or training about how to care for my youth	30 %
Lack of adaptive transportation (e.g., car that's been adapted for wheelchairs)	30 %
Lack of access to appropriate child care	27 %
Difficulty getting equipment needed for my youth's condition	27 %
Difficulty getting physical modifications in/to my home (e.g., ramps)	27 %
Not knowing where to find services for my youth	25 %
Out of pocket costs	25 %
Difficulty finding nursing care	25 %
Not having adequate respite support (short-term relief for caregivers)	23 %
Not having access to specialty doctors (e.g., few/none near me)	23 %
My personal mental and/or physical health	18 %
Lack of reliable transportation	11 %

3.4. Comparison of anticipated & experienced barriers

Table 8 presents the average ratings of barriers among all groups. ANOVAs were significant for the following barriers: not receiving enough education/training about how to care for youth ($F_{[2]} = 3.1$; $p = 0.05$); not receiving enough information about what specific needs their youth has ($F_{[2]} = 3.7$; $p = 0.03$); difficulty getting physical modifications into their home ($F_{[2]} = 3.7$; $p = 0.03$); and lack of adaptive transportation ($F_{[2]} = 10.2$; $p < 0.001$). Post-hoc analyses indicated that the difference between past and prospective foster parents was significant for the education/training barrier ($p = 0.04$) and lack of adaptive transportation ($p < 0.01$), suggesting that these barriers are less highly rated by past foster parents compared to prospective foster parents. Finally, post-hoc analyses indicated that the difference between current and prospective foster parents was significant for the barriers regarding not receiving enough information on the youth's specific needs ($p = 0.03$), difficulties in getting physical modifications into the home ($p = 0.03$), and the lack of adaptive transportation ($p < 0.001$), suggesting that these barriers are less highly rated by current foster parents compared to prospective foster parents.

The following analyses compares average barrier ratings among foster parents with lived experience (i.e., current and past combined) and prospective foster parents. The following barriers were rated, on average, as more highly anticipated by prospective foster parents than reported by foster parents with lived experience: lack of adaptive transportation ($t_{[83]} = -4.3$; $p < 0.001$); difficulty getting physical modifications into their home, such as ramps ($t_{[85]} = -2.7$; $p < 0.01$); difficulty getting equipment needed for their youth's condition ($t_{[85]} = -2.1$; $p = 0.04$); not receiving enough education/training about how to care for youth ($t_{[86]} = -2.1$; $p = 0.04$); and not receiving enough

Table 8

Comparison of average ratings for experienced & anticipated barriers.

Barrier	Current	Past	Prospective	p-value [†]
Not receiving enough education/ training about how to care for my youth	3.3	2.9	3.8	0.05
*Prospective-past**				*0.04*
Not receiving enough information about what specific needs my youth has	3.1	3.7	4.1	0.03
*Prospective-current**				*0.03*
Not knowing where to find services for my youth	3.9	3.2	3.5	–
Not having access to specialty doctors (e.g., few/none near me)	3.4	3.2	3.2	–
Difficulty getting physical modifications in/to my home	2.4	2.4	3.5	0.03
*Prospective-current**				*0.03*
Difficulty getting equipment needed for my youth's condition	2.8	2.7	3.5	–
Difficulty finding nursing care	2.5	2.8	3.3	–
Lack of reliable transportation	2.0	1.8	2.3	–
Lack of adaptive transportation (e.g., car that's been adapted for wheelchairs)	1.8	2.3	3.7	<0.001
*Prospective-current****				*<0.001*
*Prospective-past***				*<0.01*
Not having adequate respite support (short-term relief for caregivers)	3.8	3.8	3.5	–
Lack of access to mental or behavioral support resources for my youth (e.g., 24 h crisis interventions)	3.7	3.8	3.9	–
Out of pocket costs	3.1	2.7	3.6	–
Lack of access to appropriate child care	3.6	3.6	3.3	–
My personal mental and/or physical health	3.0	2.9	3.4	–

* $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$. [†] Post-hoc analyses of barriers only included if ANOVA is significant.

information about what specific needs their youth has (t[87] = −2.0; p = 0.05).

4. Discussion

This study sought to investigate the experienced and anticipated needs of current, past, and prospective foster parents regarding caring for youth with SHCN. Comparisons between groups seeks to not only identify areas for improving support for foster parents of youth with SHCN, but also increase successful recruitment of new foster parents. While limited differences were observed between current and past foster parents, the differences noted between experienced and prospective foster parents highlight how child welfare systems can improve recruitment of foster parents.

Consistent with existing literature (Brown & Rodger, 2009; Cooley et al., 2019; Khoo & Skoog, 2014), current and past foster parents reported significant challenges in managing difficult behaviors and accessing mental or behavioral services. This reiterates the need for increased mental health supports for youth in care, with supports designed to be specifically accessible to youth with SHCN. Behavioral challenges can often be a major source of stress for parents of youth with SHCN (Baker et al., 2003; Cooley et al., 2019; Herring et al., 2006; Neece et al., 2012; Woodman et al., 2014), as youth may exhibit patterns of aggression, self-injury, or other challenging behaviors (Einfeld & Tonge, 1996; Emerson et al., 2001). Traditional mental health services may not always be equipped with the necessary expertise and resources to address the specific behavioral issues associated with SHCN, particularly when working with youth with developmental disabilities. As a result, parents may struggle to find appropriate strategies to effectively manage their child's behaviors (Vohra et al., 2014).

Moreover, existing literature supports the notion that parents of children with SHCN often lack access to mental or behavioral services (Leathers et al., 2019; MacGregor et al., 2006). These challenges extend beyond youth in foster care and impact all children with SHCN. This lack of accessibility can worsen parental stress and hampers their ability to provide optimal care for their children, which can be further exacerbated for foster parents who often have even less access to parenting supports than biological parents. It is crucial to recognize that parents of children with SHCN require specific mental health supports as well to optimally care for youth with SHCN.

Previous literature emphasizes that building parent community is imperative to supporting the wellbeing of youth with SHCN and their caregivers (Cooley et al., 2019). This study's findings support this notion, with current and past foster parents reporting that cultivating a strong network and community can provide parents with moral support and guidance in navigating the foster and health care systems. Difficulty obtaining respite care and specialized day care, as well as delays in accessing services and supports, were also reported as significant barriers to caring for youth with SHCN. Ensuring adequate respite and day care options are available to foster parents is crucial to promote parent mental health and allows parents to continue working and complete other daily tasks that are limited without additional support.

Prospective foster parents reported being least open to fostering youth who are non-ambulatory or wheelchair-bound, as well as youth with technology-dependent needs and severe sensory issues. The perception that these care needs are more challenging to manage is reflected in the barriers rated as more concerning among prospective foster parents compared to experienced foster parents (e.g., difficulty getting physical modifications into the home and lack of adaptive transportation). Additionally, prospective foster parents expressed concerns about not receiving enough information or training on how to care for their youth. Comprehensive education and training specifically focused on unique care needs, as well as clarifications of myths regarding specific categories of needs, would likely benefit prospective foster parents when they are deciding whether to accept a placement.

4.1. Recommendations

Foster parents engage with multiple systems at the family, community, and institutional levels, all of which interact with one another to shape youth's care. A healthy and supportive family environment, access to community resources, and system-level supports are crucial for facilitating positive outcomes for families and youth in their care, particularly when youth have a SHCN. Thus, application of this study's findings can inform the development of targeted foster parent supports at each level to promote placement stability and appropriate care for youth with SHCN.

Foster care support organizations provide a platform for foster parents to connect with others who share similar experiences, learn about available resources, and receive training and guidance. While institutional agencies can be more challenging to influence, mediating structures (e.g., organizations situated between the individual and institutional levels) tend to be more flexible to community needs and provide a community-based platform for advocacy and shared resources (Berger & Neuhaus, 1996). Thus, the family and community-level recommendations below target community-based organizations (CBOs), while institutional-level recommendations target child welfare agencies.

4.1.1. Family-level recommendations

The opportunity for expanded SHCN-specific training was highlighted among all parent groups, including additional training and capacity-building for parents to manage behavioral issues. Given the high prevalence of behavioral challenges among youth in care (Jones et al., 2012; Sullivan & Knuston, 2000), and the impact of unsupported behavioral issues on caregiver burnout (Goemans et al., 2018) and reduced self-efficacy (Ahn et al., 2017), equipping foster parents with tools to manage, understand, and cope with behaviors is critical to prevent placement disruptions and poor outcomes. Providing resources adapted specifically for youth with SHCN is imperative, given these children can experienced increased rates of behavioral concerns.

Furthermore, building parent capacity to advocate for their youth's needs and obtain necessary information is critical for long-term success with fostering youth with SHCN. For example, training for new foster parents could include what to ask at the beginning of placements (e.g., youth's existing care plans, medical and behavioral history, how to find respite support, etc.) and how to escalate concerns when questions are not addressed.

To better equip foster parents to navigate complex systems, provide personalized, strengths-based care, and advocate for the youth's specific needs, a more engaged, customized style of training is recommended, including guiding foster parents through the youth's current care needs and medical history in a format that is clear and concise. Furthermore, while initial training is provided upon licensure, ongoing training for each youth's specific needs is often lacking at the start of each placement. As foster parents gain experience, providing iterative and on-demand training opportunities they can access independently may be more beneficial and relevant during different stages of the fostering experience while granting foster parents the agency to improve their own care practices.

4.1.2. Community-level recommendations

Previous literature and findings from this study have suggested that a sense of belonging to a network or community of other foster parents can improve morale and reduce the likelihood of placement termination (Cooley et al., 2019; Rhodes et al., 2001). CBOs have the opportunity to facilitate support groups, peer networks, and resource sharing among foster parents. Connecting new foster parents with seasoned foster parents may be beneficial as individuals with lived experience may be more familiar with available resources, how to navigate complex systems, and have built connections over time.

Also consistent with previous literature (Brown & Rodger, 2009; Ward et al., 2006), foster parents reported receiving inadequate

information about their youth's needs at the time of placement. To ensure the success of the child and foster parent, it is crucial to immediately connect foster parents to the youth's entire care team to ensure continuity of care. A dedicated role solely focused on guiding foster parents through training, obtaining resources, insurance issues, or other obstacles could expedite access to the unique care that youth with SHCN need.

CBOs can also enhance support for foster families by increasing the availability of respite care resources. Respite care is short-term, temporary relief for foster parents and can be provided by other licensed foster parents, the youth's biological family, after school programs, health care facilities, and day cares. These services allow foster parents to rest and recuperate from the daily stresses of parenting, fulfill personal obligations, and care for their personal mental and physical health. However, child care facilities equipped for caring for youth with complex needs, especially in certain geographical regions, may not exist (Anderson, 2022; Brown & Rodger, 2009; Sharda, 2022). Thus, CBOs have an opportunity to reduce the siloed nature of agencies across the state by connecting licensed parents with others outside their agency interested in providing respite.

Further, CBOs can support new and prospective foster parents by connecting parents with mentorship or peer training opportunities. For instance, seasoned foster parents can provide comprehensive insight into the experience of caring for youth with SHCN, share practical tools necessary to care for youth with various diagnoses, and address perceived concerns of prospective foster parents, such as those reported by participants in this study. These knowledge sharing opportunities can better prepare new and prospective foster parents in handling specific experiences and challenges associated with caring for youth with SHCN.

Additionally, foster parents require assistance in terms of self-care, stress management, and social support to build resilience and maintain the energy needed to care for youth with SHCN (Anderson, 2022). While all caregivers of youth likely deal with the high demands and expectations of parenting, caring for youth with SHCN presents unique emotional challenges for foster parents, including navigating multiple systems, managing relationships with biological families and caseworkers, and coordinating with the youth's care team (Brown & Rodger, 2009; Whitt-Woosley et al., 2020). Without support, these demands can lead to caregiver burnout, which can be amplified by other socioeconomic and systemic factors (Caicedo, 2014; Olsson & Hwang, 2008; Sellmaier, 2022). CBOs can be crucial in connecting parents with emotional support services and advocating for new foster parents to prioritize self-care.

4.1.3. Institutional-level recommendations

Foster parents often face long processing times waiting for approval of services urgently needed for the child, leading to potential negative impacts on the youth's health outcomes and missed opportunities for early intervention. Furthermore, limited access to healthcare providers who accept Medicaid can result in delayed access to essential services for youth and create a burden on parents who may need to travel long distances to obtain necessary services for the child. The impact of these barriers could be reduced through the approval of concurrent services (e.g., receiving therapeutic services while awaiting approval of other necessary services), establishing clear approval timelines and communication channels with families, and streamlining procedures to ensure timely access to necessary services.

Furthermore, youth in care often lack appropriate formal diagnoses (Szilagyi et al., 2015), which limits access to specialized designations and services for tailored services or placements. These designations often facilitate access to early intervention services, which enhance developmental outcomes and quality of life while preventing onset of secondary health conditions (American Academy of Pediatrics, Committee on Children with Disabilities, 2001; Centers for Disease Control and Prevention, 2022). The absence of formal diagnoses and established services can lead to fragmented medical history, inconsistent treatment,

difficulty managing chronic conditions, and disrupted relationships with healthcare providers (Christakis et al., 2001; Fontanella et al., 2015). Thus, it is essential for agencies and larger systems to establish standardized assessment protocols and a clear mechanism to flag youth diagnoses to ensure consistent and comprehensive evaluation of youth in care.

4.2. Study limitations

The following limitations should be considered when interpreting the findings of this study. First, the survey was only conducted in English due to translation and resource limitations, which likely limited the participation of individuals who are not proficient in English. Second, while electronic dissemination of the survey has advantages in terms of larger outreach, it may raise concerns about representation and potential biases in the survey results. Although the community partner has a broad reach across agencies, there is still the potential to miss certain segments of the target population. Not all foster parents may be connected to the community partner's network, and some may not use the specific communication channels through which the survey was distributed. Further, this distribution method may exclude individuals with limited digital literacy, access to devices, or internet connectivity, which can lead to underrepresentation and potentially biased results. This recruitment strategy may also introduce a selection bias, as respondents who chose to participate may not be representative of the entire foster parent population, and their experiences may differ from those who were not reached or chose to not participate.

Third, there is a lack of representation in terms of race and ethnicity in this study's sample. Independent data collection and publication efforts across the country have estimated that foster families in Illinois are 34 % White, 24 % Black/African American, 1 % Native American/ Alaskan, 1 % Asian, 4 % Hispanic/Latinx, and 40 % unknown (The Imprint, 2022). In contrast, 60 % of participants in this study's sample identified as White and 6 % identified as Black/African American, with no participants identifying as Native American/Alaskan or Asian. However, it is difficult to precisely compare demographics of our sample to all foster parents in Illinois due to disjointed database structures throughout the Illinois foster care system. While DCFS licenses families statewide, private agencies independently manage their own databases. Thus, to the research team's knowledge, there is no public statewide database of foster parents in the state of Illinois. Regardless, future research should consider more targeted recruitment among underrepresented populations to achieve a sample that mirrors the diversity and characteristics of the state's foster parent population. Further, there is limited variability in geographic location, with the majority of participants who provided geographical information residing in Northern Illinois and Cook County (n = 44; 73 %) and only 27 % of participants residing in Central and Southern Illinois (n = 16). This likely limits the generalizability of our findings to other populations and geographical regions.

Additionally, it is possible that the three barriers excluded from the prospective foster parent survey (e.g., delays in accessing services, lack of clear communication between providers, and lack of support for managing youth's behavior) are concerns among this group. The research team acknowledges that the exclusion of these barriers could be a potential limitation of our findings among prospective foster parents, especially given how highly rated these barriers were among experienced foster parents. Future research could consider exploring these questions to gain a deeper understanding of anticipated barriers and concerns. Further, there were high rates of unreported data among demographic questions and some barrier measures due to skipped items, which may affect the comprehensiveness and statistical power of our data. Finally, the sample size for qualitative responses in each individual group was small, which may limit our ability to draw conclusions about the experiences of all foster parents of youth with SHCN. This work could benefit from other qualitative methods (e.g., focus groups, guided

interviews, etc.) and further exploration until saturation is reached.

5. Conclusions

Ensuring foster parents have the necessary services, capacity-building opportunities, and support to care for their youth with SHCN is critical to youth's development, long-term outcomes, and placement stability. Understanding the first-hand experiences of foster parents is a crucial first step to developing supports for foster parents of youth with SHCN at the institutional, community, and family levels. By ensuring these resources are available to foster families, we can better support the critical role that foster parents play in the care of youth with SHCN and improve outcomes for these vulnerable youth.

CRediT authorship contribution statement

Spencer St. Jean: Formal analysis, Visualization, Writing – original draft, Writing – review & editing. **Ashley Murphy:** Conceptualization, Project administration, Writing – original draft, Writing – review & editing. **Kendra Wright:** Conceptualization, Project administration, Writing – original draft, Writing – review & editing. **Clara Law:** Conceptualization, Methodology, Project administration, Writing – review & editing. **Heather J. Risser:** Conceptualization, Investigation, Methodology, Supervision, Writing – original draft, Writing – review & editing.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Data availability

The data that has been used is confidential.

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