

Frequencies and Types of Unmet Needs of Families with Children and Youth with Special Health Care Needs Undergoing a Preparedness Intervention

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Introduction: Families with children and youth with special health care needs (CYSHCN) have unique and enhanced considerations for staying safe in emergencies. When these families also have social determinants of health (SDOH) hardships, achieving household preparedness may be particularly difficult. Our objective was to implement a virtual home preparedness intervention (VHPI) to identify and address the unmet SDOH and preparedness needs in a diverse sample of families of CYSHCN recruited from medical homes across Pennsylvania.

Methods: The VHPI included (1) CYSHCN-centered pre/post interviews addressing medical needs, household preparedness, and SDOH; (2) information and support for emergency planning (eg, go-bag supply list, gift card) and local resources (eg, for housing assistance); and (3) individualized, as-needed referrals to professionals in the medical home or community partners (eg, American Red Cross, family-to-family health information centers, medical-legal partners). Interviews were conducted from April 2020 to June 2022 during which needs were identified and referrals were made and tracked. Needs then were coded and counted by type sample-wide, per-participant, and within sociodemographic subgroups.

Results: The CYSHCN of focus had reliance on medical equipment (68%), physical mobility needs (48%), communication or intellectual challenges (79%), and/or vision or hearing loss (36%). Among participants who completed the pre-VHPI (n = 170) and the post-VHPI (n = 148) interviews, SDOH hardships were prevalent and included food insecurity (20%) and housing insecurity (8%) (Table 1). A total of 1072 needs were identified and addressed through referrals; 279 of these pertained to emergency preparedness tasks. SDOH-coded needs fell into each of the Healthy People 2030 domains, especially Healthcare Access and Quality (558 needs) (Table 2). On average, 6 needs were noted per participant (range, 0 – 27 needs), with more needs associated with participants who primarily spoke a language other than English (additional median needs, +4), rented their home (+2), or lived in a household with another individual (other than the CYSHCN) with a disability or functional need (+1.5) (Table 3).

Conclusions: Families with CYSHCN have many unmet SDOH and preparedness needs. The VHPI, coupling preparing for emergencies with addressing SDOH hardships, may be an opportunity to address both in a routine care visit for CYSHCN.

Table 1. Pre/post responses to the VHPI interview items related to SDOH

SDOH-Related Interview Item	Rate Affirmed	
	Initial Interview (pre)	Follow-up Interview (post)
Has no reliable and skilled backup caregiver for CYSHCN ^a	10.1% (17/168)	15.1% (22/146)
Has no community support (eg, extended family, friends, place of worship) to rely on if an emergency were to occur	8.3% (14/169)	6.2% (9/146)
Has a household member without health insurance	17.8% (30/169)	13.1% (19/145)
Has received public assistance in the past year (food stamps, WIC, cash assistance, TANF) ^b	68.6% (116/169)	66.2% (96/145)
In the past 3 months, was “sometimes” or “often” worried that the household would run out of food before they had money to buy more	20.5% (34/166)	17.4% (25/144)
In the past 12 months, had trouble paying for utilities (eg, gas, water, electric, phone)	33.3% (56/168)	23.8% (34/143)
Has difficulty making home more accessible for CYSHCN ^c	43.7% (45/103)	36.9% (31/84)
Has difficulty getting home repairs	14.8% (25/169)	11.7% (17/145)
Has issues with rodents, insects, or other pests in the home	23.2% (39/168)	24.8% (36/145)
Is worried about not having a permanent home to stay in or becoming homeless ^d	8.0% (13/163)	7.8% (10/128)
Is afraid of being hurt by a partner or family member ^d	3.2% (4/124)	1.0% (1/98)
In the past 2 weeks, has “often” or “sometimes” felt down, depressed, or hopeless ^d	36.2% (50/138)	42.7% (47/110)

^aNot including a home nurse or hired caregiver.

^bDoes not include unemployment. This item included a “not eligible” response option.

^cThis item included an “NA” (not applicable) response option, for participants whose children did not have home accessibility challenges.

^dThis item included a “Decline” option, in addition to yes/no.

CYSHCN, child/youth with special healthcare needs; SDOH, social determinants of health; TANF, Temporary Assistance for Needy Families; VHPI, virtual home preparedness intervention; WIC, Women, Infants, and Children.

Table 2. Needs identified in the study sample (n = 170 participants; 1072 total needs) addressed through referrals to the medical home or community partners, by category

Need Category ^a	Number of Needs Identified	Need Subcategory	Representative Needs	
Disaster and emergency preparedness	279	168	Notification/information	Medical alert bracelets, up-to-date medical care plan summary
		23	Power/SIP	Backup power plan, SIP plan
		27	Fire safety	Smoke/CO alarms, fire extinguishers, light-up or bed shaker alarms (for CYSHCN with hearing loss)
		46	Supplies/equipment	Emergency supply of medication, gravity feeding bags, generator (for CYSHCN with technology reliance), emergency supplies of food and water
		15	COVID-19 disruptions	Care interrupted due to pandemic (loss of services/therapies, schooling, transportation), death of a caregiver from COVID-19
Economic stability	123	46	Access to public assistance	Difficulty receiving SSI, SSD, SNAP, child tax credit, LIHEAP
		50	Difficulty paying bills	Difficulty affording utility bills, internet or phone service, renters' insurance
		27	Food insecurity	Difficulty affording food or identifying local food banks
Healthcare access and quality	558	31	Insurance/coverage	Lack of health insurance for CYSHCN or other members of household, unnecessarily paying OOP for covered supplies
		66	Mental health resources	Positive screening results for depression/mental health concerns, new emotional or behavioral symptoms in CYSHCN, desire for connection to therapist or support group
		52	Medications or prescriptions	Inadequate supply of prescription medication or formula, unable to access pharmacy
		23	Vaccines	Negative or unknown vaccine status for COVID-19, flu, other, request for vaccine counseling
		332	Medical equipment or services	Missing or inadequate DME or other supplies (respiratory, gastrointestinal, mobility, sensory, hygiene)
		54	Access to providers	Difficulty making appointments with dietitian, PCP, PT, OT; issues implementing care plans; unknown diagnosis or new unaddressed symptoms
Neighborhood and built environment	51	13	Housing stability	Concerns about becoming unhoused, need for assistance applying for Section 8 housing
		26	Housing safety	Ongoing pest problems, home repairs needed, concerns about neighborhood crime, lack of heating/air conditioning
		3	Accessibility of housing	Limitations of property preventing ramp installation
		9	Landlord tenant disputes	Pest problems or repairs/modifications not being addressed by landlord
Social and community context	44	25	Caregiver support	Disruption or lack of home nursing, lack of family support or emergency/backup caregivers
		19	Other social/community need	Problems with language access, screened positive for IPV, guardianship concerns
Education access and quality	17	Enrollment, inadequate special education resources or disability accommodations, concerns about safety/abuse at school		

^aNeeds were coded into mutually exclusive categories of emergency preparedness (the focus of the VHPI) or 1 of the 5 Healthy People 2030 SDOH categories.

CO, carbon monoxide; COVID-19, coronavirus disease 2019; CYSHCN, child/youth with special healthcare needs; DME, durable medical equipment; IPV, intimate partner violence; LIHEAP, Low Income Home Energy Assistance Program; OOP, out of pocket; OT, occupational therapist; PCP, primary care provider; PT, physical therapist; SDOH, social determinants of health; SIP, shelter in place; SNAP, Supplemental Nutrition Assistance Program; SSD, Social Security Disability; SSI, Supplemental Security Income; VHPI, virtual home preparedness intervention

Table 3. Needs subgrouped by sociodemographic characteristic in the study sample of families with CYSHCN

Variable Category	Variable Type	No. (%) of Participants (n = 170)	Mean No. of Identified Needs	Median No. of Identified Needs (Range)	Difference in Median No. of Needs
Caregiver preferred language	English	144 (84.7)	6.0	5 (0-27)	4
	Spanish/Other ^a	26 (15.3)	8.4	9 (0-15)	
CYSHCN has medical equipment or utility dependence	Yes	115 (67.6)	6.5	6 (0-27)	1
	No	55 (32.4)	5.9	5 (0-23)	
CYSHCN has physical mobility need	Yes	82 (48.2)	7.0	6 (0-27)	1
	No	88 (51.8)	5.6	5 (0-23)	
CYSHCN has intellectual or communication challenge	Yes	135 (79.4)	6.5	6 (0-27)	1
	No	35 (20.6)	5.7	5 (0-15)	
CYSHCN has vision or hearing loss	Yes	62 (36.5)	6.1	6 (0-15)	0
	No	108 (63.5)	6.4	6 (0-27)	
CYSHCN no. of diagnostic categories	1	50 (29.4)	5.6	5 (0-23)	---
	2	46 (27.1)	5.9	5 (0-15)	0
	3	44 (25.9)	7.4	6.5 (0-27)	1.5
	4	30 (17.6)	6.4	8 (0-16)	3
Income level (above/below \$25k HHI/year or missing)	Above	62 (36.5)	5.7	5 (0-16)	---
	Below	52 (30.6)	7.1	6 (0-27)	1
	Missing	56 (32.9)	6.2	5 (0-18)	0
Homeownership status	Own	62 (36.5)	5.4	5 (0-16)	---
	Rent	101 (59.4)	7.0	7 (0-27)	2
	Other	7 (4.1)	4.9	5 (0-9)	0
Residential classification	Urban	151 (88.8)	6.3	6 (0-16)	1
	Rural	19 (11.2)	6.1	5 (0-27)	
Reliable backup caregiver	Yes	152 (89.4)	6.4	6 (0-27)	1
	No	17 (10.0)	5.9	5 (0-14)	
Uses home nursing or home health services	Yes	79 (46.5)	6.5	6 (0-23)	1
	No	91 (53.5)	6.1	5 (0-27)	
Employment status	Full time/more than one job	52 (30.6)	5.4	5 (0-13)	---
	Part-time	29 (17.1)	6.1	6 (0-16)	1
	Unemployed	89 (52.4)	6.9	7 (0-27)	2
Others in household with disability or functional need	Yes	72 (42.4)	7.1	7 (0-27)	1.5
	No	98 (57.6)	5.7	5.5 (0-18)	

^aHaitian-Creole (n = 1), Brazilian Portuguese (n = 1)

CYSHCN, child/youth with special healthcare needs; HHI, household income