# Respite Care for Children with Home Mechanical Ventilation

ARCH Respite Research Summit

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I have no relevant financial relationships to disclose



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# Funding


- The Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD, K23 HD097276)
- T73 Leadership Education in Neurodevelopmental and Related Disorders Training Program (LEND, T73MC11047).

# Objectives

1. Definition of pediatric population qualifying for respite care
2. Discuss distinct opportunities and challenges for *pediatric* respite care
3. Describe current barriers to respite care for families of children with medical complexity
4. Plan for next steps in Pediatric Respite Care research



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# Objective 1

Definition of pediatric population qualifying for respite care



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# Children with Home Mechanical Ventilation (HMV)

**Respiratory or Neurologic**

Chronic lung disease of prematurity

Hypoventilation syndrome

Cervical spinal cord injury

Spinal Muscular Atrophy

http://www.uwppc.org/educational-resources/self-study-modules/pediatric-tracheostomy-ventilator-care/trach/section4/



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# Objective 2

Discuss distinct opportunities and challenges for *pediatric* respite care



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Presumption of parent as caregiver

Presumption of young children as limiting time away



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Adults with the same level of medical complexity often live within a nursing facility

https://www.npr.org/sections/health-shots/2020/03/04/812162416/as-coronavirus-looms-many-nursing-homes-fall-short-on-infection-prevention



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# Respite care for the pediatric population

- Caring for a child with special healthcare needs can be unrelenting, constant, stressful
- Respite can be beneficial for marital relationships, sibling, and the children themselves
- However, the benefits may be countered with the societal expectation to care for your child full-time and respite use being perceived as parental failure

(Whitmore, Snethen, Journal for Specialists in Pediatric Nursing 2018)



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# Respite care for Children with Medical Complexity

- Additional hours of home care nursing
- Respite care in a specialized facility like Almost Home Kids



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Almost Home Kids™
Share the Care

*"Almost Home Kids is a short-term community based pediatric healthcare facility that brings together Medical Professionals, Recreational Volunteers, Community Providers, Sponsors, Donors, Friends, Corporate and Civic Partners. AHK is licensed by the Department of Public Health."*

Three services:

- Transitional Care
- Respite Care
- Respite Care Transportation

Three Locations

- Naperville IL
- Chicago IL
- Peoria IL

Figure 2. (A) Almost Home Kids Chicago downtown site. (B) Child life specialist plays with a patient. (C) Nurse reads to a patient. (D) Almost Home Kids Chicago suburban site.

https://www.almosthomekids.org/



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SPECIAL ISSUE ARTICLE

# Prolonged Hospital Discharge for Children with Technology Dependency: A Source of Health Care Disparities

Sarah A. Sobotka, MD, MSCP; Rishi K. Agrawal, MD, MPH; and Michael E. Msall, MD

## ABSTRACT

Children with ventilator assistance have been supported in living at home since 1981 when parental advocacy ushered in a change to Medicaid policy. As the population of children who use medical technology such as long-term ventilation increases, we must critically evaluate our systems for preparing families for home life. Discharge delays persist in the modern era because of fragmentation between hospital and home systems. These discharge delays result in children spending time in less developmentally rich environments, further exacerbating the health and development disparities of children with complex disabilities. In this article, we discuss the complication of hospital discharge and how it contributes to health and developmental disparities. We also describe a hospital-to-home transitional care model, which presents a home-like environment to provide developmental support while focusing on parental training, home nursing, and public-funding arrangements. **[*Pediatr Ann.* 2017;46(10):e365-e370.]**

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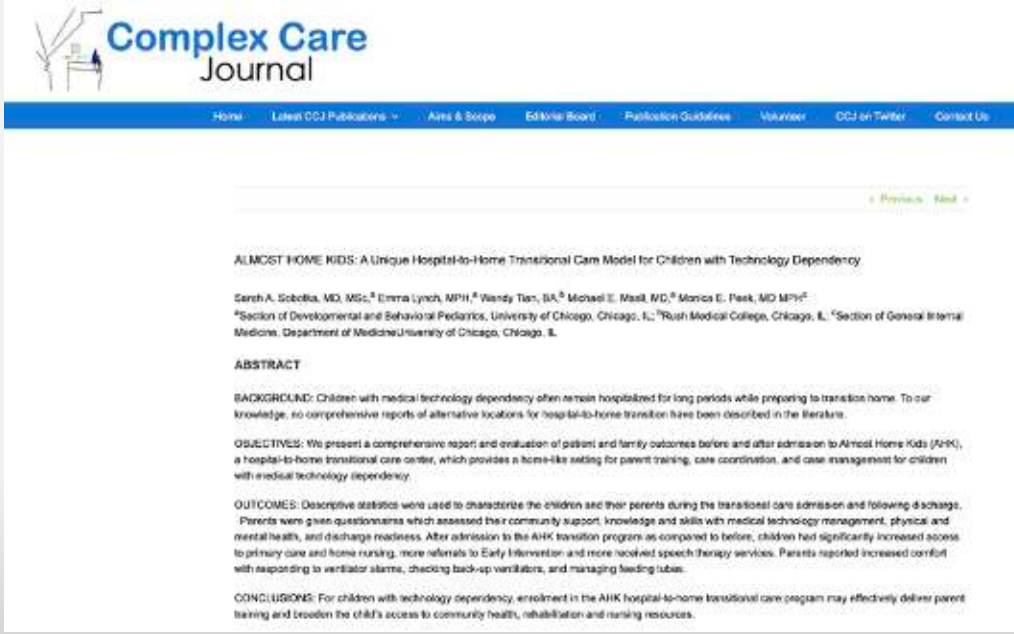
doi:10.3928/19382359-20170919-01

More than 35 years ago Julie and Mark Beckett, the parents of Katie Beckett, led an advocacy campaign, which led to a 2-fold change in federal Medicaid policy that benefited children with technology dependence. First, parents could qualify for Medicaid based on having a child with severe disabilities and needing community health and rehabilitation services. Second, Medicaid insurance would pay for this complex care in the home.[1,2] Prior to this time, children with ventilator dependency were often unable to receive services at home, and instead remained indefinitely in a hospital or a skilled nursing facility.

On June 22, 1999, the United States Supreme Court upheld the right of people with disabilities to live in the community through the *Olmstead v. L.C.* decision.[3] This landmark case maintained that public entities should make reasonable accommodations for community-based services for people with disabilities. For example, when possible, health care services should be provided in community settings, such as acute care, intermediate care, rehabilitative care, or nursing homes, instead of more restrictive hospital settings.[4] Ten years later, the Americans with Disabilities Act prohibited discrimination against people with disabilities in regard





# Objective 3

Describe current barriers to respite care for families of children with medical technology dependence



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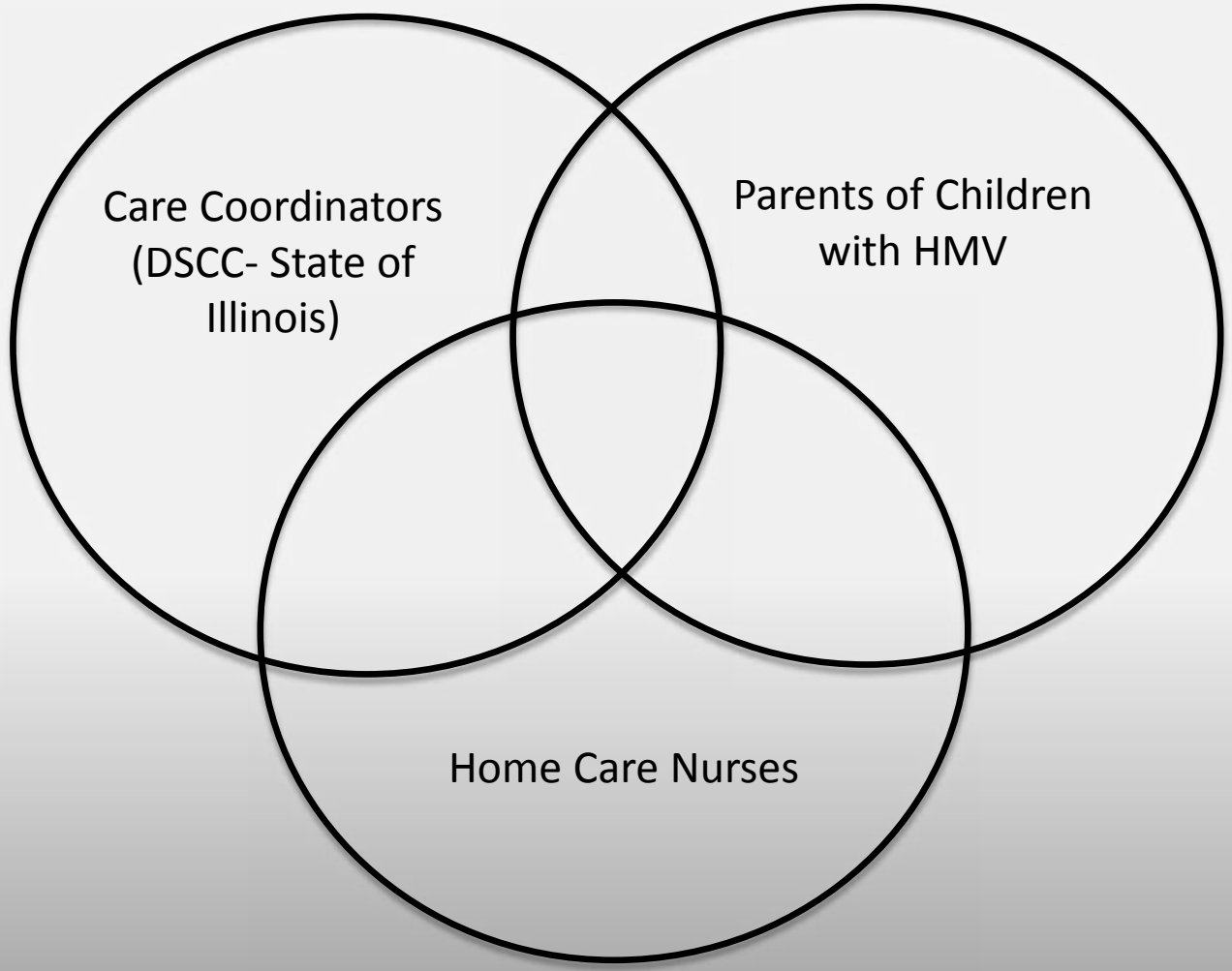
# 3 Key Informant Groups



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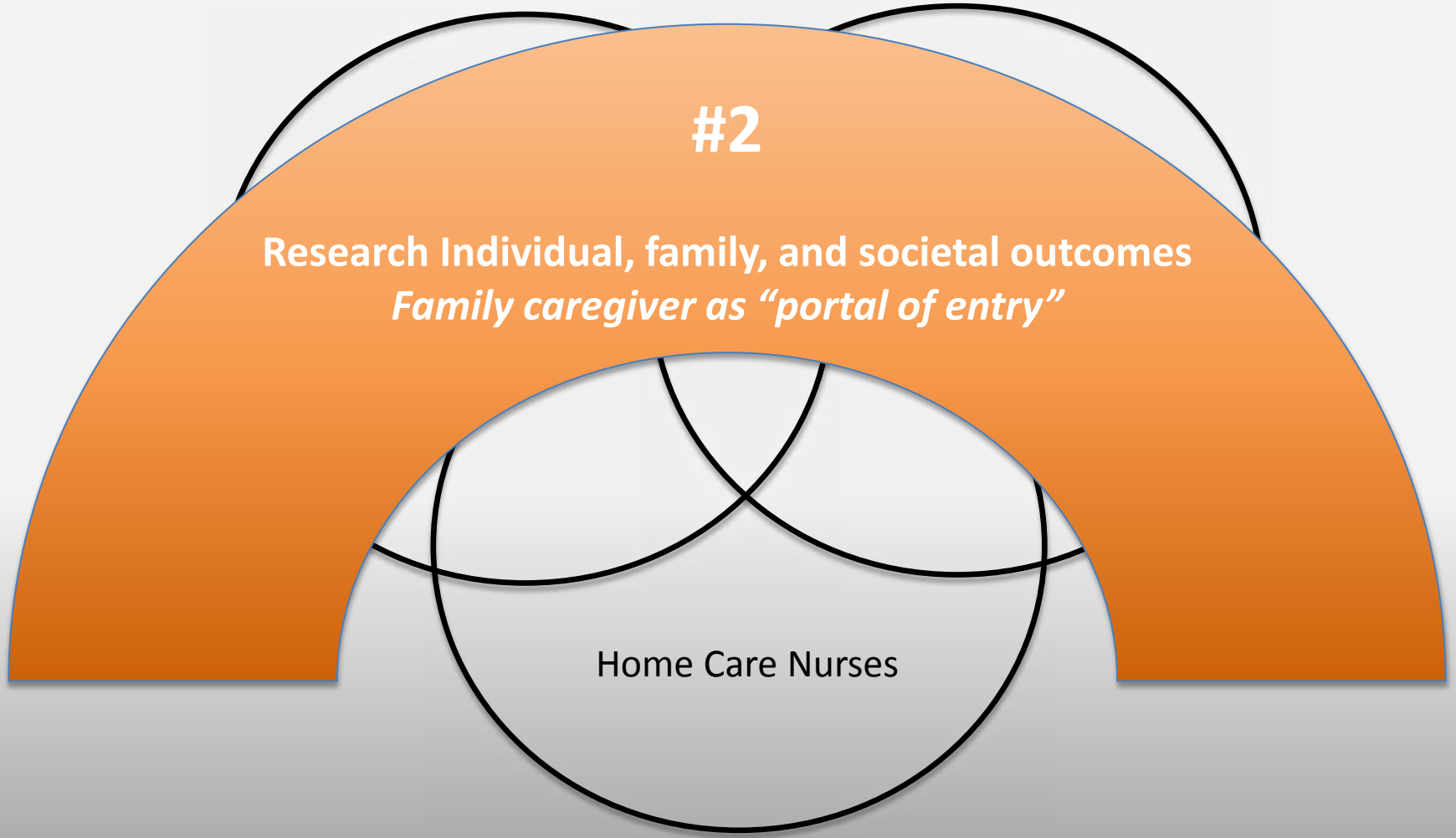
# 3 Key Informant Groups



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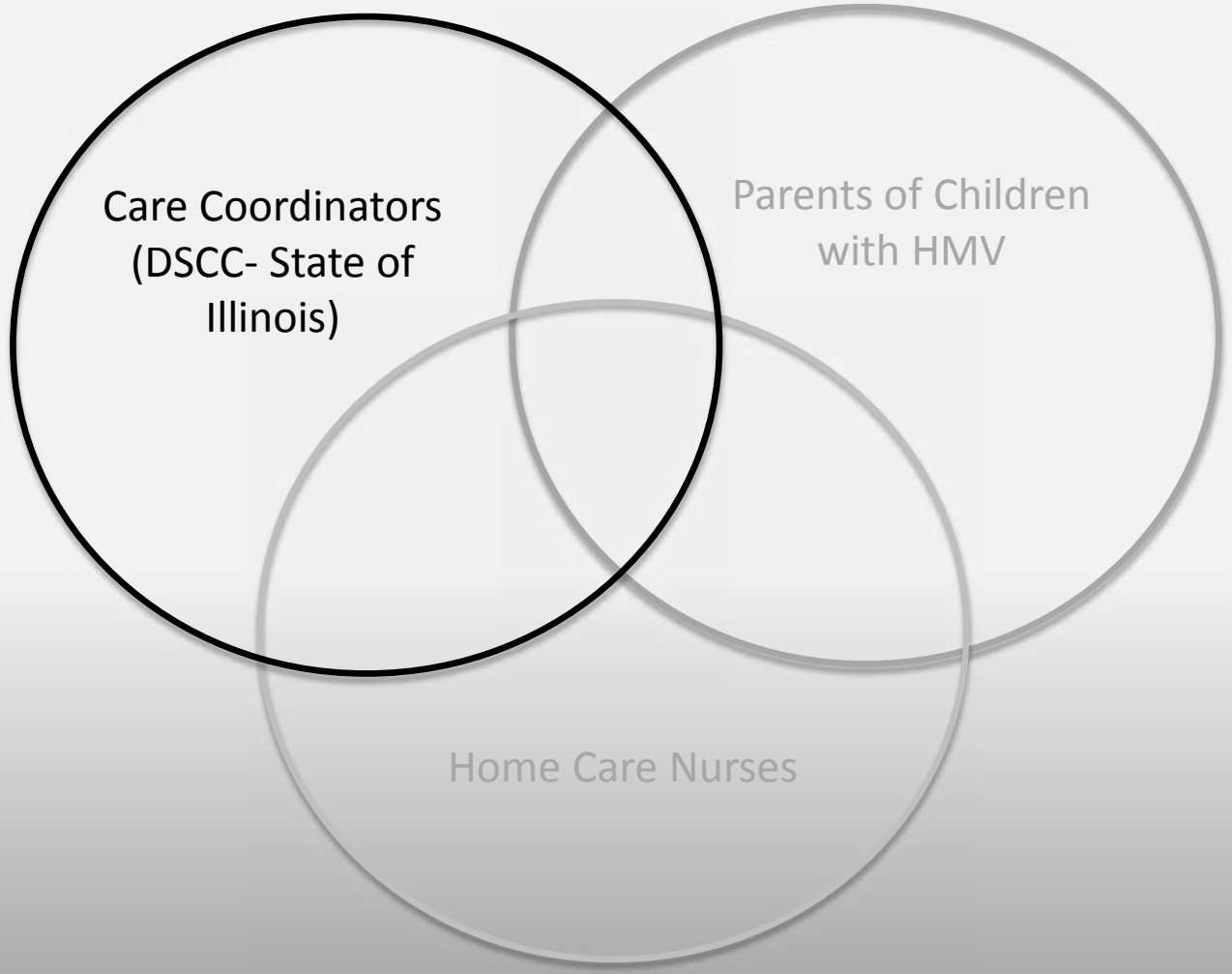




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# UIC Division of Specialized Care for Children(DSCC)

- State of Illinois care coordination program for children with medical complexity
- The Home Care program for children who have medical fragility and require skilled nursing care at home
- Nearly all children in the state with ventilator dependency receiving home nursing are enrolled



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*Article*

# Unmet Respite Needs of Children With Medical Technology Dependence

Clinical Pediatrics
2019, Vol. 58(11-12) 1175–1186

DOI: 10.1177/0009922819870251
journals.sagepub.com/home/cpj
SAGE

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**Abstract**

Children with medical technology dependency (MTD) require a medical device to compensate for a vital body function and substantial nursing care. As such, they require constant high-level supervision. Respite care provides caregivers with a temporary break, and is associated with reduced stress; however, there are often barriers. The study utilizes mixed methodology with the National Survey of Children with Special Health Care Needs (NS-CSHCN) and semistructured interviews with state-wide care coordinators to understand the gap for respite care services. Fifty-nine percent of parents who needed respite care received none. Parents of older children with MTD were more likely to report respite needs. Care coordinators described that home health shortages created barriers to respite care utilization, and the lack of respite care can lead to hospital readmission. Although respite care is a vital resource to support families of children with MTD, it is infrequently available, which can have severe consequences.

**Keywords**

children with medical complexity, respite care, home care, children with disabilities, caregiving

# Methods

- Mixed methods study
  - Survey data from parents/guardians of children with MTD within the 2009/2010 National Survey of Children with Special Health Care Needs (NS-CSHCN)
  - Semi-structured interviews with care coordinators for a state-wide


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# Methods- Quantitative

- National Survey of Children with Special Healthcare Needs (NS-CSHCN)
- Cross sectional study, 2009/10
- Sampling and data: State and Local Area Integrated Telephone Survey (SLAITS)
  - Random digit dialing
  - The survey was conducted in all 50 states and in D.C. from July 2009 to March 2011


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# Inclusion criteria

- Home Health
- Durable Medical Equipment
- Child was described as having at least one of the following diagnoses ever in their lifetime
  - Cerebral Palsy
  - Muscular Dystrophy
  - Developmental disability
  - Intellectual disability
  - Epilepsy
  - Head injury
  - Heart problem
  - Cystic fibrosis
  - Down syndrome


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# NS-CSHCN Respite Definition

"care for the child so the family can have a break from ongoing care of the child. Respite care can be thought of as child care or babysitting by someone trained to meet any special needs the child may have. Both professional and non-professional respite care should be included."



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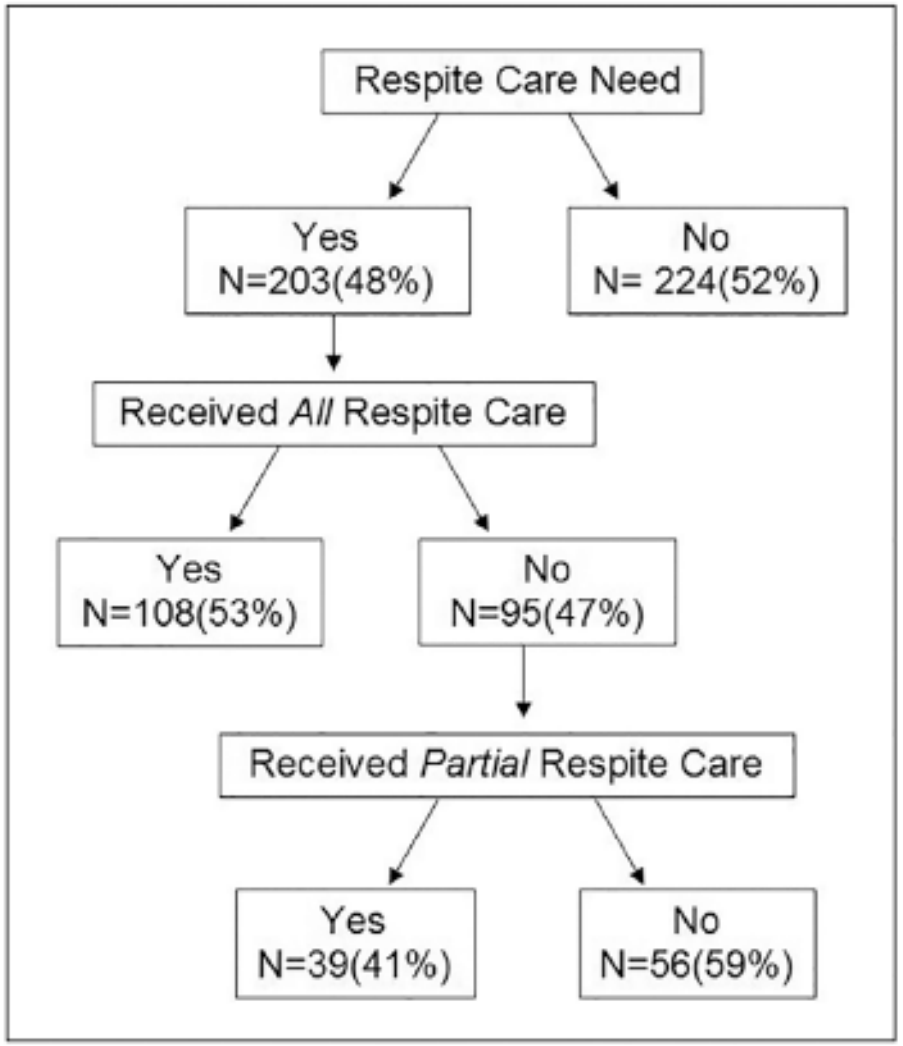


**Figure 1.**
Parents of children with medical technology dependency responses to respite care questions in the National Survey for Children with Special Healthcare Needs (NS-CSHCN).

**Table 1.** Demographic Characteristics of Children with Medical Technology Dependence in NS-CSHCN 2009-2010 (N=427)

| Characteristic | N | % |
|---|---|---|
| **Age (years)** | | |
| <1 | 29 | 7 |
| 1-2 | 63 | 15 |
| 3-4 | 54 | 13 |
| 5-9 | 132 | 31 |
| 10-17 | 149 | 35 |
| **Gender** | | |
| Male | 253 | 59 |
| Female | 174 | 41 |
| **Race/Ethnicity** | | |
| Non-Hispanic White | 289 | 68 |
| Non-Hispanic Black | 35 | 8 |
| Hispanic | 58 | 14 |
| Other | 45 | 11 |



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**Table 1.** Demographic Characteristics of Children with Medical Technology Dependence in NS-CSHCN 2009-2010 (N=427)

| Characteristic | N | % |
|---|---|---|
| **Household Income (% Federal Poverty Level*)** | | |
| <100 | 111 | 26 |
| 100-199 | 103 | 24 |
| 200-399 | 132 | 31 |
| Greater than or equal to 400 | 81 | 19 |
| **Insurance Type** | | |
| Public Insurance | 217 | 51 |
| Private Insurance | 78 | 18 |
| Both Public and Private | 115 | 27 |
| Uninsured/Other Insurance | 17 | 4 |
| **Family Structure (N=418)**** | | |
| Two parents biological/adopted | 255 | 61 |
| Single mother | 104 | 25 |
| Other | 59 | 14 |
| **Highest Education Level of Primary Caregiver** | | |
| Less than high school | 30 | 7 |
| High school | 73 | 17 |
| More than high School | 324 | 76 |



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Reasons Families of Children With Medical Technology Dependence Did Not Receive Respite Care in the National Survey of Children With Special Health Care Needs (N = 94).

| Reasons for Not Receiving Respite Care | N (%) |
|---|---|
| Not available in area/transportation problems | 22 (23) |
| Cost | 13 (14) |
| Insurance barriers | 13 (14) |
| Not convenient times/could not get appointment | 11 (12) |
| Provider did not know how to treat or provide care | 9 (10) |
| Did not know where to go for treatment | 8 (9) |
| Dissatisfaction with provider | 3 (3) |
| Treatment ongoing | 3 (3) |
| Referral barriers | 2 (2) |
| Other | 42 (45) |



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# Methods- Qualitative

- Eligible care coordinators emailed invitation to participate:
  - Work as care coordinator for at least 1 year
  - Interviews completed in Care Coordinator's office site at day and time convenient for them
- Study Design: In-depth semi-structured qualitative interviews with care coordinators
  - Many topics respite was just one


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**Table 1.** Demographic Characteristics of Care Coordinators

| Characteristic | N (%) |
|---|---|
| **Age (years), mean (range)** | 45.2 (28-57) |
| **Female** | 14 (93) |
| **Race/Ethnicity** | |
| Non-Hispanic White | 7 (47) |
| Non-Hispanic Black | 6 (40) |
| Hispanic | 2 (13) |
| **Total household income** | |
| 50-99K | 11 (79) |
| 100-150K | 3 (21) |
| **Marital status** | |
| Non-Married | 4 (27) |
| Married/Living as Married | 11 (73) |
| **Years in care coordinator role, mean (range)** | 6.6 (1-27) |
| **Educational Background** | |
| Registered Nurse | 5 (33) |
| Masters in Social Work or Counseling | 8 (52) |
| Physical Therapy/Occupational Therapy | 2 (13) |



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# Transcript analysis

- Stage 1: Creation of Preliminary codebook
  - Modified Template Approach to coding*
  - Initially based on interview guide
  - Expanded based on emerging themes
- Stage 2: Open Coding-Thematic Coding
  - SS and EL complete independent summative coding of transcripts
  - Discuss to agreement
- Stage 3: MAXQDA Coding- Hypothesis building
  - SS and EL complete coding with codebook using MAXQDA program
  - Compute inter-rater reliability and revise codebook every transcript initially; then transition to every 2-3 transcripts



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# 4 Major Themes

- Theme I: Care Coordinators' Perception of Respite Care
- Theme II: Examples of Families' Use of Respite Care
- Theme III: Barriers to Respite Care Use
- Theme IV: Respite-Related Readmissions



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# Care Coordinators Perceive Respite Care as **an essential service**

"You need it. It's vital."

"I think it's wonderful. I'm pretty sure a lot of them feel guilty, but you have to take time for you. And I tell parents that all the time. Like, 'Yes, you love your child. But you're gonna probably be in this for 10, 15, 20, 30, years. You have to find that time to reconnect. Even if it's once every three months, you have to find some time for yourselves.'"

"It's wonderful for her. Because that's what the respite is for. It's for the parent ... you can just take a break."



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# Care Coordinators Perceive Respite Care as **underutilized**

"I think it's underused. It's really underused. I think the families who I have who are using it are using it more to patch in, like to make a full shift, once a week. I have a family, child, he gets the minimum resource allocation, so it doesn't make five complete shifts. So the family is whittling away with a little bit of respite every week."

"I don't have a lot of experience with respite care. I've only had maybe two cases where the family wanted to go somewhere."

"I have not had any families who have taken advantage of respite."



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# Care Coordinators' Experiences with Respite Care

"In the event that the family has a vacation or they have to do something where they're unable to take this medically fragile child with them, they can always opt to have them go to one of these transitional facilities, so that they receive round the clock nursing services."

"I have a mom—twice a year she goes to Jamaica, because she's from—once a year. She'll take her son. She has 24-hour coverage while she's away. And she's usually gone from four to five days. And that's how she utilizes her respite."



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# Care Coordinators' Experiences with Respite Care

"A lot of families use respite care if they're working, to add on to shifts, so the nurse can stay a little longer."

"An illness. A parent goes into the hospital, and there's not another trained caregiver. Emergency traveling. You know, another state or country, for a family funeral, or that kind of stuff, is what I've also seen it used for.

"Some families have used respite where they may need to paint the home, and the child can't be there."



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# Care Coordinators' Experiences with Respite Care Barriers

"I really don't have a lot of people using respite.... In order to use respite, you have to be using all of your regular hours ... if these cases aren't fully staffed, they can't even use their respite."

"Unfortunately, sometimes it's not always available. Sometimes the beds are not available. So those families that do decide to go on a trip and leave their child in the transitional care and the respite facilities, and they can't, because there's no beds available for them."



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# Care Coordinators' Experiences with Respite Care Barriers

"I have a family—the parents are from India ... and [the respite care center] didn't have any beds ... so the family arranged with [another respite care center], to take him, and it was all set. [But] sure enough they used the bed for something else. And so what this family did instead of mom and dad going to India together, Dad went first, mom stayed home with him, and then they flip-flopped."

"Some families just are like, 'No, it's my child, and I can't leave them somewhere else. And they're exposed to god know what there.' You know, infection, whatever."



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ORIGINAL ARTICLE: OUTCOMES

WILEY

# Readmission drivers for children with medical complexity: Home nursing shortages cause health crises

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## Abstract

**Objective:** Children with medical technology dependence (MTD) are frequently readmitted to the hospital. However, due to their medical fragility, it is often difficult to untangle the root causes for readmissions to identify the most effective preventive approaches. We sought to explore environmental and family factors driving hospital readmissions for children with MTD.

**Design:** Semi-structured, in-person interviews were conducted with state-wide care coordinators for children with MTD in Illinois with at least 1 year of experience. Interview topics related to children with MTD transitioning from hospital-to-home, essential supports for living in the community, and factors which influenced and prevented hospital readmission. The interview guide served as an initial codebook which was iteratively modified as themes emerged.

**Results:** Fifteen care coordinators with on average 6.6 years of experience were interviewed. They described that lack of home nursing was one of the primary drivers of readmissions due to parental exhaustion and lack of medical expertize in the home. Unavoidable medical admissions, a lack of a plan for emergencies, and home environmental factors also contributed to readmissions.

**Conclusion:** Hospital readmission is an expected occurrence for children with MTD, yet still may be substantially reduced through consistent, quality home health nursing to bolster family capacity and allow for respite from constant caregiving. Improved incentives for the home health workforce to increase manpower would be ultimately offset by reduced hospitalizations for children with MTD. Additionally, more research is needed to understand which home nursing structures and skills optimally support families in the reality of manpower scarcity.

KEYWORDS
bronchopulmonary dysplasia, children with medical complexity, home healthcare, mechanical ventilation, noninvasive ventilation, private duty nursing, readmissions

# Respite-Related Readmissions

"Sometimes we see increased number of medical complications and even hospitalizations or ER visits, that possibly could have been avoided if there was better nursing support."

"I have a family who had a mice infestation in their apartment.... The nurses—they weren't going to work there, and nursing stopped. And then mom has three other kids. There's a dad, but he works all the time. And eventually the child was hospitalized because it was just too much. No nursing, mice running around, just mom."



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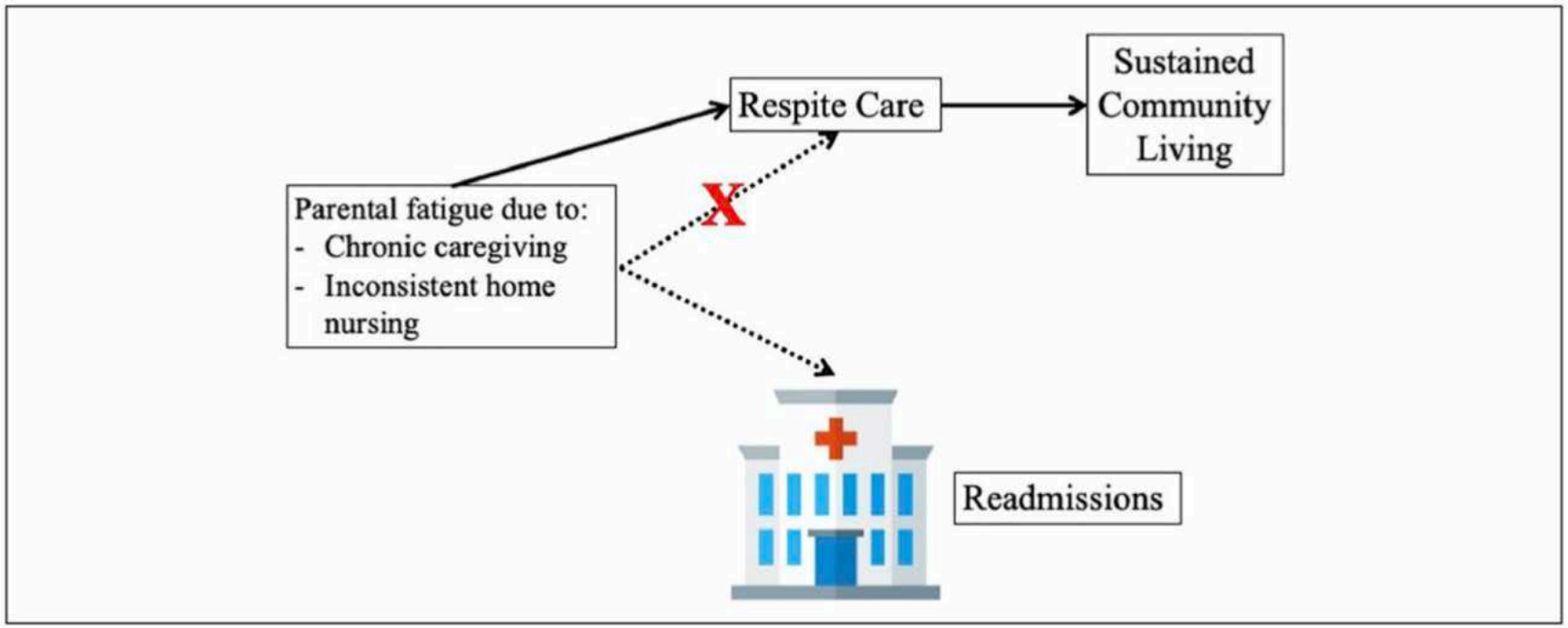


**Figure 2.**
Conceptual model for impact of lack of respite care on hospital admissions.

# Conclusions

- Lack of respite providers and centers makes access to respite care often impossible.
- The shortage of home health providers block intermittent reprieve for families
- The lack respite provision results in otherwise avoidable readmissions to the hospital.



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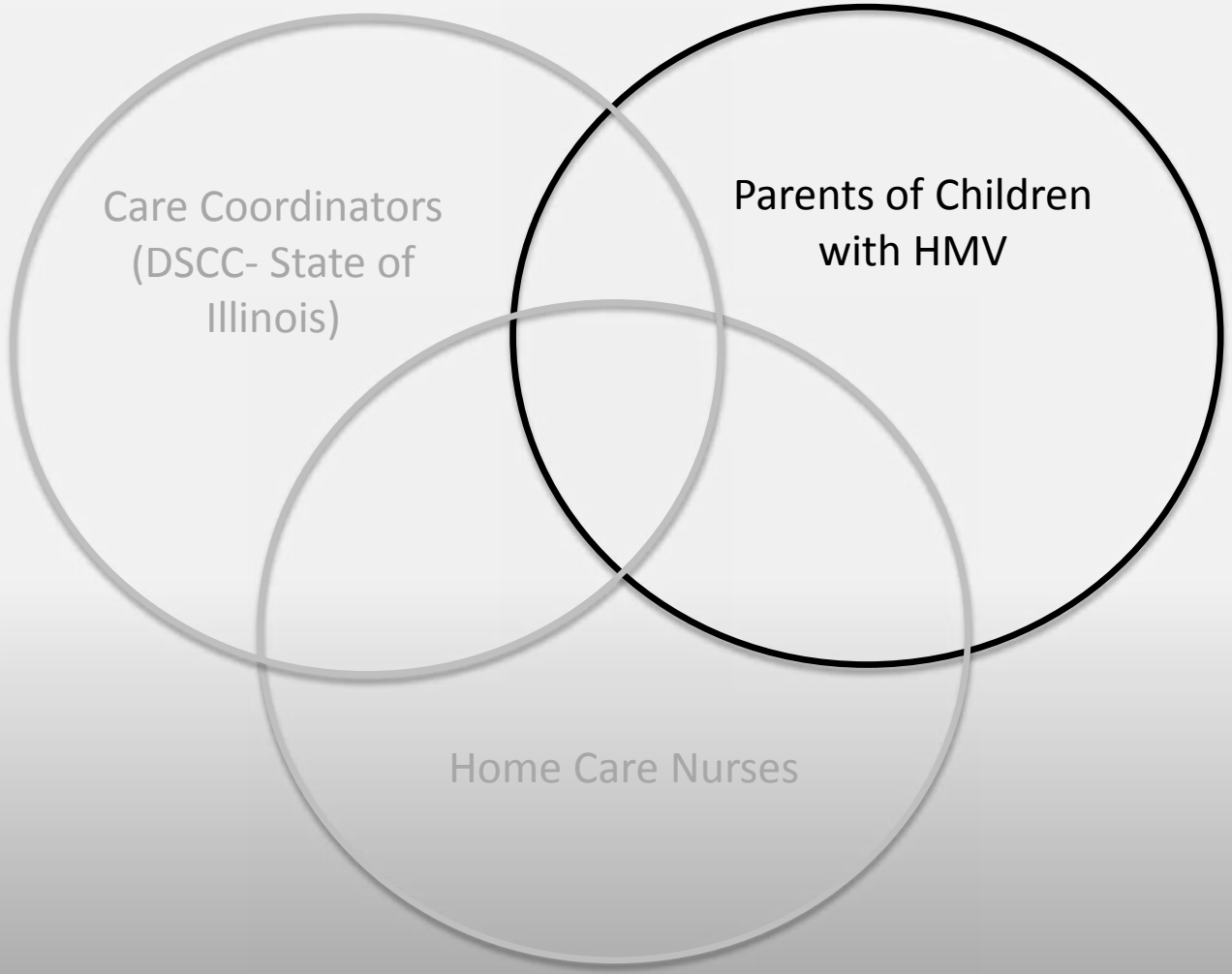
# 3 Key Informant Groups



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# Family Study

- Enrollment criteria:
  - Families of children with home mechanical ventilation
  - Transitioning home from the hospital for the first time
  - Enrolled in the DSCC Home Care Program
- Longitudinal with visits at at 1 month, 6 months, 1 and 2 years after discharge
- Parents participate in semi-structured interviews
- Developmental testing with the children


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**Table 1.** Demographic Characteristics of Children with Home Mechanical Ventilation (N=12)

| Characteristic | N (%) |
|---|---|
| **Age (months), mean (range)** | 13 (5-30) |
| **Female** | 7 (58) |
| **Race/Ethnicity** | |
| Non-Hispanic White | 5 (42) |
| Non-Hispanic Black | 4 (33) |
| Hispanic | 2 (17) |
| Would Rather Not Say | 1 (8) |
| **Total household income** | |
| Less than 50K | 6 (50) |
| 50-99K | 2 (17) |
| 100-149K | 2 (17) |
| 150K+ | 1 (8) |
| Would Rather Not Say | 1 (8) |
| **Marital status** | |
| Non-Married | 3 (25) |
| Married/Living as Married | 9 (75) |
| **Highest Educational Level of the Household** | |
| High School Degree | 1 (8) |
| Some College | 6 (50) |
| College Degree | 4 (33) |
| Advanced Degree | 1 (8) |



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# Lack of knowledge about respite

- “I don’t know much about it. I just know it’s more available hours, if I'm correct.”



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# Cannot access because baseline nursing need is not met

"We haven't even hit our allotment, and the way that our nursing is scheduled is there's two hours per week that we won't hit anyway."



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# Cannot imagine leaving child

"Right now, I can't fathom that idea. And it's not just cause it's early; it's because I would hate myself, in a way."

"The last thing I want to do is dump her off somewhere. I just need her to be home, like all day."

"It's not—it's like a kennel. That just doesn't sit right with me."

# Potential for Respite Care Utilization

"I really do want to take advantage of that respite care, and if we've got something going on, then maybe we could have an overnight shift over the weekend."

"I mean, I think if [sibling name] were older, and it's like the prime time to go to Disney World, it's like, "OK, maybe.""



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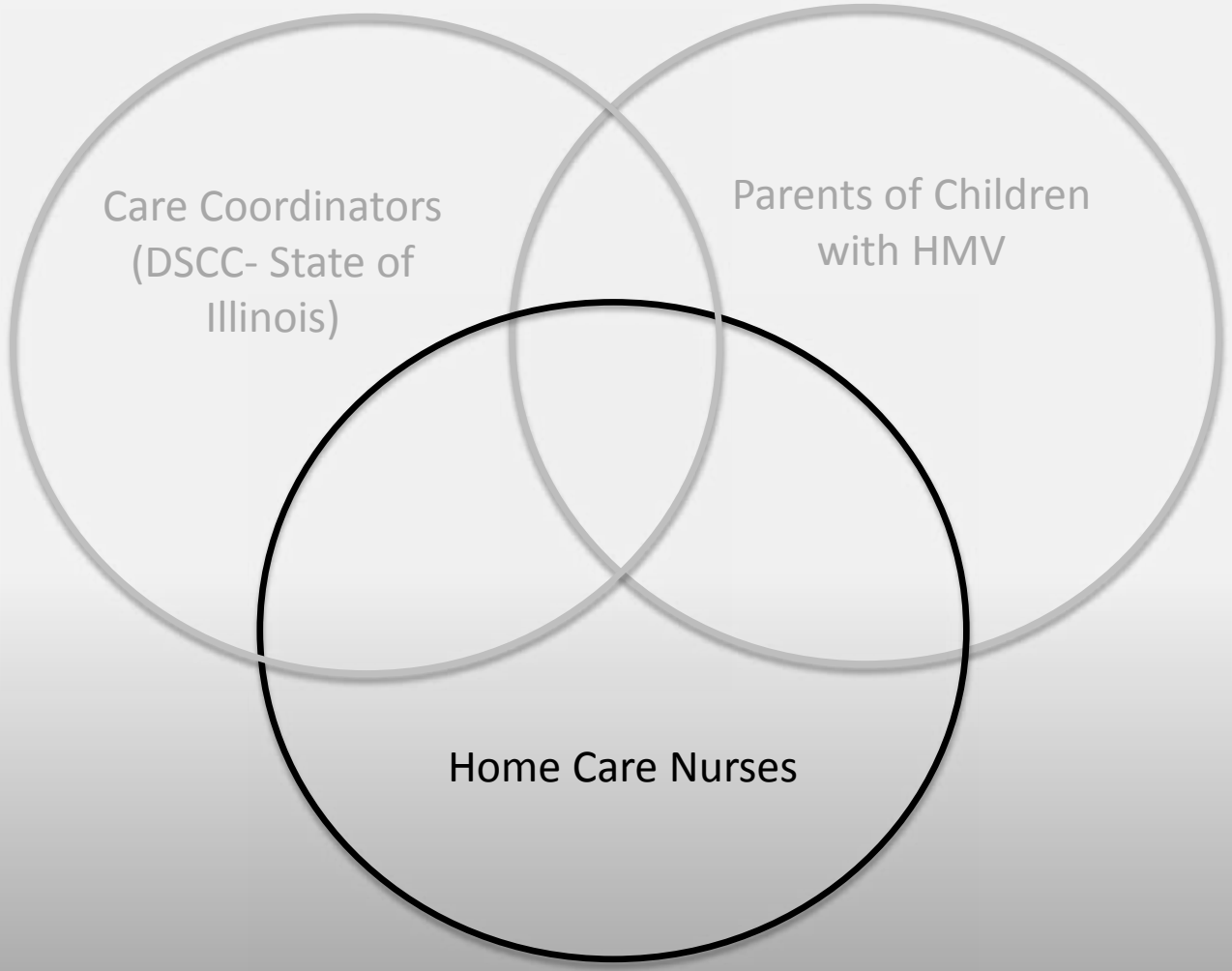
# 3 Key Informant Groups



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# Home Nursing Study

- Enrollment criteria:
  - Must have worked/currently work as a home care nurse with children with home mechanical ventilation
- Nurses participate in semi-structured interviews



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**Table 1.** Demographic Characteristics of Home Care Nurses (N=12)

| Characteristic | N (%) |
|---|---|
| **Age (years), mean (range)** | 45 (23-68) |
| **Female** | 11 (92) |
| **Race/Ethnicity** | |
| Non-Hispanic White | 9 (75) |
| Non-Hispanic Black | 2 (17) |
| Hispanic | 1 (8) |
| **Total household income** | |
| Less than 50K | 1 (8) |
| 50-199K | 9 (75) |
| 200K + | 2 (17) |
| **Marital status** | |
| Non-Married | 8 (67) |
| Married/Living as Married | 4 (33) |
| **Years in Home Nursing role, mean (range)** | 17 (1-36) |
| **Educational Background** | |
| Licensed Practical Nurse | 2 (17) |
| Registered Nurse | 7 (58) |
| Bachelors of Science of Nursing | 3 (25) |



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# Home Nurses recognize importance of respite care

"I think the parents need to get away. I think they need to do that…. But I really think the family—they do need to get away, even if it's just for a weekend. Just try and let loose. And that'll build up their confidence in their nurses."

"Some have put their children in Almost Home, so they could take a vacation or something. Which I think is very nice, that at least they have that available to them. Oh, it was wonderful. It was wonderful."



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# Home Nurses have experience with respite care

"I've done 24-hour nursing for a couple of families, where they had enough committed nurses that they could use their respite hours that way, so they could get away. It wasn't for super-long periods of time, but they could get away."

"I've had families that go away. They go on vacation. Maybe they have other kids, and they're taking their other kids somewhere."



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# Objective 4

Plan for next steps in Pediatric Respite Care research



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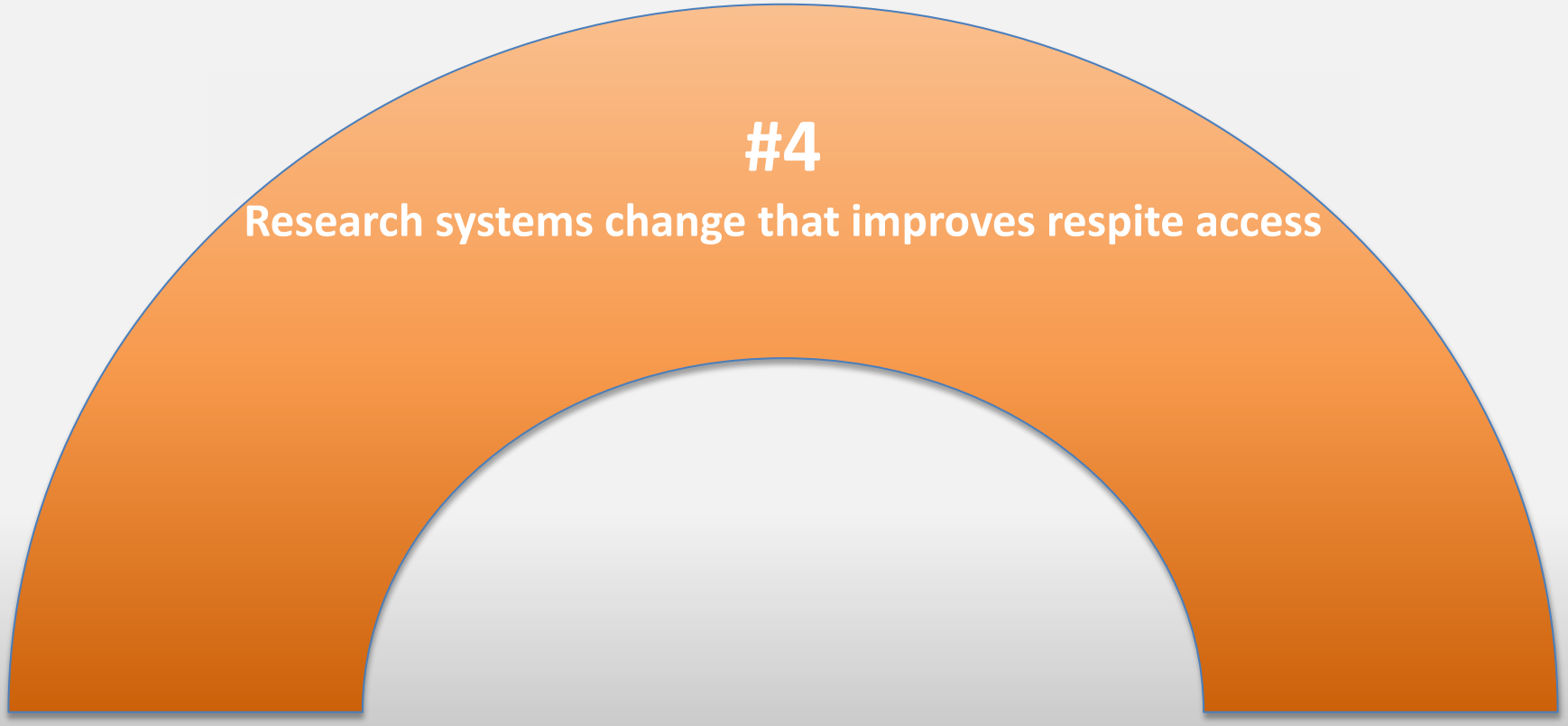
# Overall barriers to respite care



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# Overall barriers to respite care

Baseline home nursing support for children with medical complexity is drastically under available

*Baseline care needs to be fixed for in-home respite care to succeed*



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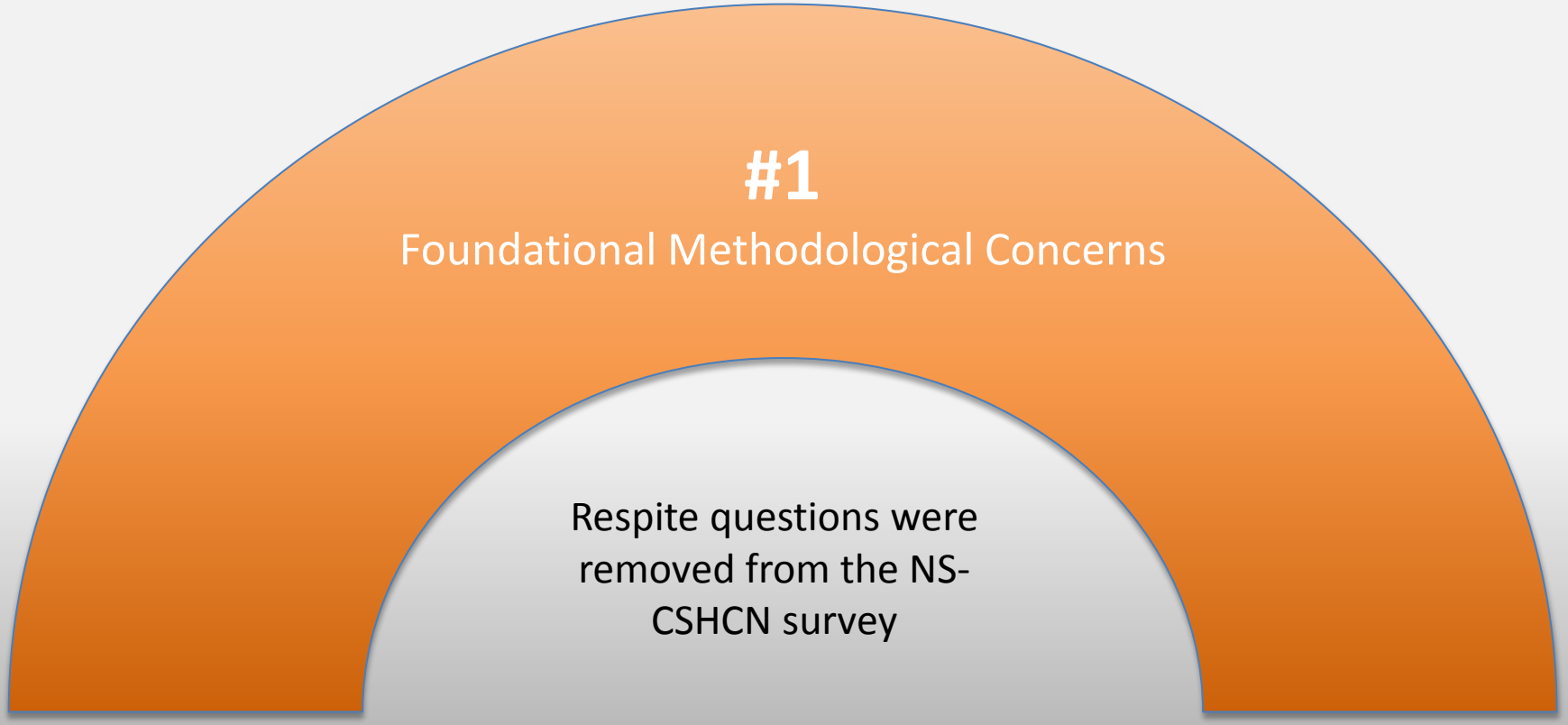
# Bring respite care to forefront of CMC dialogue



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- Research support
  - Clinical Research Coordinator: Emma Lynch, MPH

1. University of Chicago
2. Harvard University/Boston Children's Hospital

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