



## Original article

# Needs assessment of caregivers of children with disabilities in resource-limited settings

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## Abstract

**Objective:** This study aimed to identify and classify the needs of caregivers of children with disabilities living in resource-limited settings and develop a framework for need assessment.

**Participants and Methods:** This study was conducted in the Maha Sarakham Province, Thailand, with 15 caregivers caring for children with disabilities recruited from hospitals, the Association for the Disabled, and primary health centers. Semi-structured interviews were conducted in local dialects, recorded, transcribed, converted into standard Thai, and then into English for thematic analysis. Meaning units corresponding to caregivers' needs were extracted, interpreted, coded, and hierarchically organized into subcategories by comparing similarities and differences among the extracted codes. The subcategories were further grouped and abstracted into categories, and then domains of caregivers' needs were formed.

**Results:** Nineteen categories were identified across five domains of caregivers' needs: health and medical, welfare, educational, social, and informational. Although basic medical treatment was covered, specific support, such as referral to a specialist, rehabilitation, or psychological support, was limited. Financial support and relief from the care burden are the main welfare needs. Educational needs were identified to provide knowledge to children and to offer respite to their caregivers. Social needs revealed ethical problems that arose because of strong rural community ties, making it difficult to maintain privacy. Informational needs were intertwined with the other four domains. In rural areas, where parents of children with disabilities migrate to cities to find work, the special needs of grandparents who were primary caregivers of the children needed to be addressed.

**Conclusion:** This study provides a conceptual framework for comprehensive needs assessment and policy development for caregivers of children with disabilities living in resource-limited settings.

**Key words:** needs assessment, children with disabilities, caregivers, resource poor settings, Thailand

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## Introduction

Globally, over a billion people live with some form of disability, accounting for approximately 15% of the world's

population<sup>1</sup>. They have worse health access and poorer health outcomes than those without disabilities. Further, they are left behind in global health, and therefore, termed the “Missing Billion”<sup>2</sup>.

The burden of disability, including physical, mental, and intellectual disabilities, is significant in resource-limited settings, where approximately 80% of the people with disabilities live. Therefore, attaining universal access to health-care and welfare for these unprivileged populations is necessary to achieve sustainable development goals<sup>3</sup>.

Children living with disabilities are particularly vulnerable; compared with those without disabilities, they are five times at risk of severe illness<sup>4</sup>. Health outcomes of children with disabilities are related not only to their illness but also to non-illness-related factors<sup>5</sup>, such as their families' eco-

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conomic conditions, care service availability, schooling opportunity, food diversity, and caregivers' skills. Therefore, family caregivers are key to the health of children with disabilities, particularly when public support services are limited.

Caring for a child with a disability is particularly challenging for caregivers living in resource-limited settings. The availability and affordability of health care and welfare services are major obstacles for caregivers. Researchers in Uganda reported that caregivers face various challenges, including burden of care, poverty, care stress, and communication problems<sup>6</sup>. In Indonesia, researchers have found that caregivers of children with disabilities experience psychological and emotional challenges<sup>7</sup>. An ecological study in low- and middle-income countries revealed that children with disabilities are more likely to be maltreated by family members than those without disabilities<sup>8</sup>, indicating elevated stress and difficulties for caregivers. Focusing on health and medical domains is insufficient to understand caregivers' needs. The psychosocial and economic factors influencing the care of children with disabilities should also be considered, as the World Health Organization (WHO) advocated in its bio-psychosocial model<sup>9</sup>.

Inspired by the bio-psychosocial model of the WHO, this study aimed to identify and organize the unmet needs of caregivers serving children with disabilities in resource-limited settings into a hierarchical framework.

## Participants and Methods

The study was conducted in the Kantharawichai District of Maha Sarakham Province, situated in northeastern Thailand, which has a population of approximately 80,000. The Kantharawichai District is a rice-growing area situated about 20 km from the center of Maha Sarakham City, the capital of Maha Sarakham Province. This is an area from which many people migrate to cities to find work. The center of Maha Sarakham City has several hospitals, including a provincial hospital; therefore, general medical services are available to the population. However, services for chronic-condition children with disabilities who need more welfare support than medical support are limited. The Thai government disability allowance (THB 800 per month) was available for registered individuals. However, the registration rate remains less than half, and the allowance is insufficient to meet the needs of children with disabilities (5% of household expenses)<sup>10</sup>. Therefore, we conducted our study in this area as a resource-limited setting in terms of providing services for children with disabilities and chronic conditions.

Participants were recruited from hospitals, the Association for the Disabled, and primary health centers in Kantharawichai District. The inclusion criteria were 1) caregivers of children aged 18 years or younger with chronic disabilities

and healthcare needs and 2) caregivers caring for children for more than one year. Participants were screened using the Thai version of the CSHCN Screener<sup>®11</sup>. Many children in this area are infected with the human immunodeficiency virus (HIV) and they develop HIV-related disabilities<sup>12,13</sup> and were included in this study. Furthermore, in cases where parents of children with disabilities migrated to cities to find work leaving their children in the care of grandparents, we included grandparents who were considered primary caregivers of children with disabilities.

Semi-structured interviews were conducted in March 2014 in a local dialect with 15 participants caring for children with disabilities. The interviews were recorded using an IC recorder, and the participants provided written informed consent. The background information of the participants and their children are presented in Table 1.

The interview transcripts were first converted from the local dialect to standard Thai and then translated into English for analysis. The translation was double-checked by the Thai researchers. Meaning units corresponding to and exemplifying the following were extracted: difficulties in health and childcare faced by caregivers, delayed or forgone care experienced by caregivers, and unfulfilled healthcare needs. Meaning units were interpreted, coded, and grouped into subcategories by comparing the similarities and differences among the extracted codes. The subcategories were further grouped and abstracted into categories that formed the specific needs of the caregivers.

This study was approved by the ethics committees of Mahasarakham University (Thailand) and Aichi Prefectural University (Japan) (24APU6-49).

## Results

Nineteen categories of caregiver needs were identified across the five domains; they are outlined below. The categories within each domain are shown in Figure 1.

### Domain 1: Health and medical needs

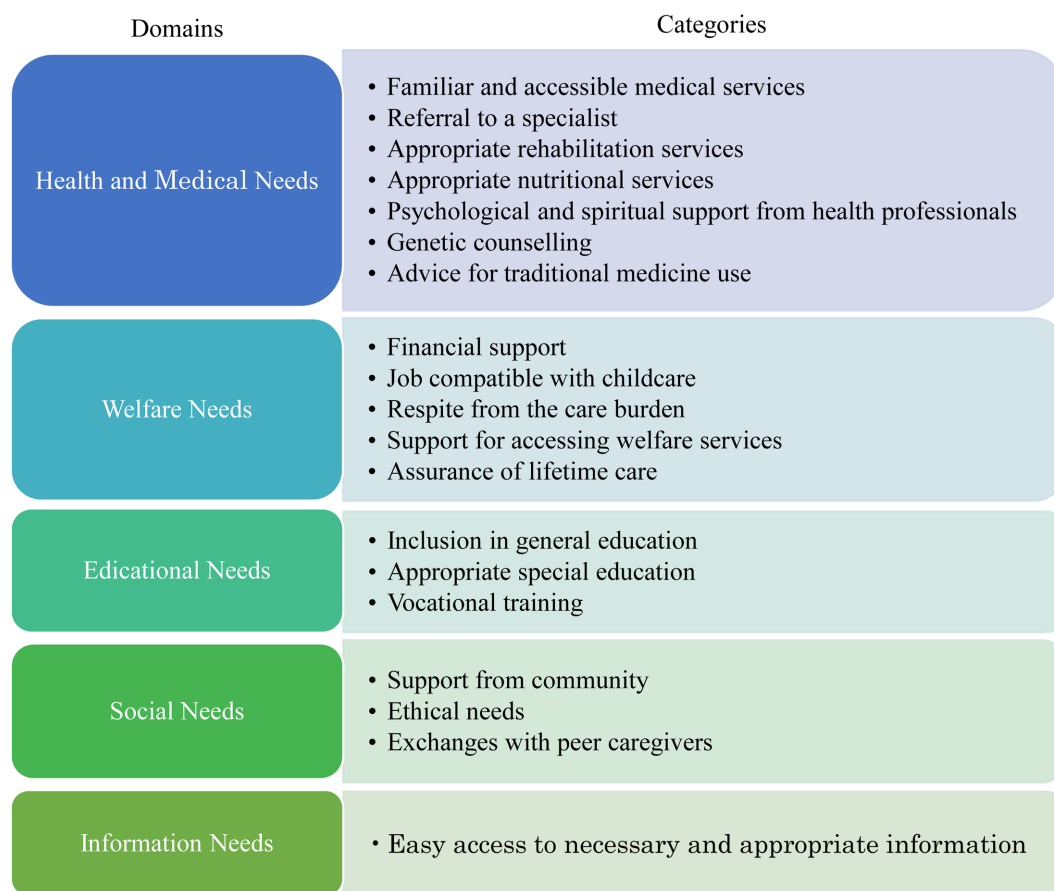
*Familiar and accessible medical services.* Although all children with disabilities underwent medical examination and treatment, their caregivers described unfulfilled needs regarding the appropriate treatment. For instance, some children received delayed access to medical examinations because their caregivers feared the diagnosis of a disease, did not follow up on the laboratory test results, and tried to believe that the children would get better.

The caregivers felt that their children were different from other children and needed special attention at hospitals and clinics. They mentioned that medical doctors, apart from pediatricians, did not appropriately understand the characteristics of children with disabilities. This need is captured below in a statement from one of our participants.

**Table 1** Socioeconomic backgrounds of participants

No.	Participant	Age	Education	Occupation	Economic status	Child age	Child sex	Child conditions
1	Grandmother	55	Primary	Farmer	Average	1y 8m	M	Microcephaly, DD
2	Father	45	Primary	Farmer	Average	18y	M	Epilepsy, DD
3	Mother	42	Junior high	Artisan	Average	14y	M	Attention Deficit Disorder
4	Mother	40	Junior high	Farmer	Average	15y	F	Cerebral thrombosis Hemiplegia
5	Mother	35	Primary	Farmer	Difficult	6y	F	Asthma, DD
6	Grandmother	44	Junior high	Farmer	Average	5y	M	Electric shock, DD
7	Mother	37	Primary	Farmer	Average	17y	F	Convulsion Mental problem
8	Mother	36	Primary	Occasional worker	Very Difficult	3y 6m	M	Muscular dystrophy Mental problem, DD
9	Grandmother	53	Primary	Farmer	Difficult	3y 9m	M	Myasthenia
10	Mother	20	Junior high	Housewife	Average	1y8m	F	Down Syndrome
11	Grandfather	67	Primary	Occasional worker	Average	15y	F	HIV
12	Father	43	Primary	Farmer	Average	15y	F	HIV
13	Mother	48	Primary	Housewife	Average	14y	F	HIV
14	Grandmother	72	Primary	Housewife	Difficult	13y	M	HIV
15	Grandmother	58	Primary	Housewife	Difficult	12y	F	HIV

y: year; m: month; M: Male; F: Female; DD: Developmental delay; HIV: Human Immunodeficiency Virus infection.



**Figure 1** Needs assessment framework for caregivers taking care of children with disabilities in resource-limited settings.

“I want them to understand these children because they are not like normal children. They can easily become frightened and tense [...]. They (the doctors) should be calmer. Whenever I tell them about E’s emotions, they always say that there is nothing to worry about. But I know my child. I want them to listen to the parents’ opinions”. (No. 5)

*Referral to a specialist.* Although caregivers had access to medical services at local hospitals, they wanted to access better services. Furthermore, some desired a second opinion. However, these efforts were sometimes futile because specialists were unavailable at accessible local hospitals and financial problems precluded long-distance travel.

*Appropriate rehabilitation services.* Along with the physical or speech therapy provided at local hospitals, caregivers of children with intellectual or developmental challenges desired additional behavioral training or developmental rehabilitation. Although therapists in hospitals initially provided the children with therapeutic services, the caregivers were eventually taught the relevant techniques and continued to perform the therapies at home. The caregivers not only practiced the techniques they had been taught but also developed their own methods of improving their child’s rehabilitation and sought tips and tools that could help them further improve rehabilitation at home.

*Appropriate nutritional services.* Children with disabilities often have specific diet and food preparation requirements; for instance, some have difficulty chewing and so their food must be mashed. Meanwhile, some caregivers believed that specific foods such as eggs or fish helped improve their children’s condition. They mentioned the need for nutritional advice as well as certain supplements to improve their child’s health.

*Psychological and spiritual support from health professionals.* Caregivers experienced a range of emotions while caring for their children. These include denial, sorrow, discouragement, fear, anger, stress, and powerlessness. Caregivers appreciated the psychological support from healthcare professionals who accepted their negative emotions and guided them on effective coping methods. In particular, caregivers reported needing encouragement and someone who listened to their experiences. Thai people are generally sympathetic to caregivers, and many caregivers mentioned that they received support from lay people. However, caregivers were not willing to discuss their situations widely; they disclosed their feelings to only a limited number of people, including healthcare professionals.

Many Thai people believe in Buddhism and often seek relief through religion and practice religious rituals to obtain peace of mind. Healthcare professionals are often themselves Buddhists and guide caregivers per their faith.

“She (an old lady) told me to buy a red and white (soft) drink and a garland to pay respect to the guard-

ian spirit and ask that F be cured [...]. I asked that F be cured and offered incense to 16 guardian spirits [...]. I shouted F’s name three times. Then, a woman (a nurse) told me to pray using Chinnabanchara (a chant) and the Chant of Metta (loving kindness) to the people we were indebted to from our past lives [...]. This helped me and my grandfather felt better”. (No. 6)

*Genetic counseling.* One caregiver wished to know whether she could have a child without a disability who could help her in her old age. Another caregiver wondered why all three children under their care had Duchenne muscular dystrophy.

*Advice on traditional medicine use.* When caregivers found that Western medicine could not cure their children, they tried traditional herbal and spiritual treatments to complement it.

“I searched for books about herbs because I hoped that such an approach might help [...]. I took B to a traditional healer, who cured him by spitting and blowing on him”. (No. 2)

## Domain 2: Welfare needs

*Financial support.* All but one of the children were officially registered in Thailand’s welfare system and either had already received a government disability allowance or were waiting to receive it. They also received other official and semi-official lump-sum subsidies. Among these, grants from the “Khun Poom Foundation,” founded by Princess Ubol Ratana Rajakanya, were very common. In addition to monetary support, caregivers received free medication and milk from special education schools.

However, all caregivers still found it difficult to obtain optimal care and support for their children’s daily needs. Financial difficulties also led them to refrain from using services. Some caregivers refused services because of the cost, whereas others felt that hospitals refused them because of their poverty.

“I took H to Bangkok. He then developed a fever. No hospital wanted to accept us because they were afraid that we would not be able to pay the medical fee”. (No. 8)

With insufficient official support, caregivers sought private support from their families and communities, although such support was usually limited.

“We regularly borrow 2,000 or 3,000 baht from our neighbors. We often borrow, although not every month”. (No. 1)

Caregivers’ financial problems were due to both the increasingly expensive care of the children and insufficient income. One of the most prominent expenses mentioned was transportation. The children received free medicine and special education; however, transportation to the facilities was at the expense of the caregivers.

*Job compatible with childcare.* Caregivers' lack of income is caused by unemployment and loss of earning capacity. Caregivers could not take full-time jobs because of childcare responsibilities. Consequently, they attempted to find jobs compatible with childcare; however, such opportunities were limited. Furthermore, some diseases attract stigma, which contributes to caregivers' difficulty in finding an appropriate job.

The study region was located in an area where many people left their homes to work. Therefore, many grandparents were caring for children with disabilities, and some of them received remittances from the parents of the children who had left to work in large cities. This reduced the financial burden but placed a childcare burden on grandparents.

*Respite from the burden of care.* Caregivers mentioned that childcare was excessively time-consuming. Children with disabilities are often difficult to manage and require attentive care. Some are particularly sensitive and hyperactive and exhibit varied behaviors than children without such conditions. Caregivers complained that they did not have time to go out or address their own needs.

"We cannot go to work. We must hurry home after we finish eating or tending our cows or buffaloes. We must take care of A in turn, even when we go to the toilet. The hardest time is when we want to go elsewhere. Sometimes, we cannot go, and we feel like crying". (No. 1)

Consequently, many caregivers expressed a need for help or supported to relieve their care burden.

"We do not know whom we should ask. Everyone is busy with their own business. We are waiting for help from the government ... but if we have to ask someone for help, we do not know whom to approach". (No. 1)

*Support for accessing welfare services.* The Thai government has established a welfare system for people with disabilities. The system includes a disability registration card, a disability allowance, and various services. Many caregivers appreciated this system; however, some mentioned that they needed assistance in negotiating complicated official procedures.

"I would like to (apply for a subsidy), but I do not know what to write, the correct words to use, or even how to start [...]. I want someone to complete the forms for me because I cannot get a subsidy if I do not apply correctly". (No. 8)

*Assurance of lifetime care.* The child's future was a primary concern for caregivers. They wanted their children to become independent and live ordinary lives. However, it is unrealistic to expect some children with serious physical or intellectual disabilities to become independent. Caregivers of such children, especially grandparents, worried if there would be someone to care for them after they passed away.

"I hope someone will adopt him so that he has a place to stay, and people who take care of him with love and who can secure doctor consultations without being forced to wait for a long time". (No. 2)

## Domain 3: Educational needs

*Inclusion in general education.* Children with disabilities who did not have severe intellectual problems participated in the general education. However, in some schools, teachers have difficulty understanding the needs of the children with disabilities. Some caregivers found that teachers wanted children with disabilities to study as much as other students did, making them feel nervous and uncomfortable.

"He cannot read, but he can sing. While he was in fifth and sixth grades, he could sing without being nervous [...]. When he goes to school, teachers want students to study hard. For school activities, such as watering plants, he can do anything other children do. However, in a lecture, he cannot stay in the class for more than 20 minutes. I do not know what to do". (No. 3)

Some caregivers sensed that their children felt inferior to other children at school and wanted them to receive equal treatment.

"Now K does not go to school ... She said that she does not want to go because she makes mistakes [...]. I want them (the teachers) to treat K like a normal person [...]; I do not want her to have an inferiority complex". (No. 11)

*Appropriate special education.* Many interviewees expressed the need for special education in boarding-type schools. This was partly because of the expectation that this could help children become self-reliant and relieve their caregivers' heavy care burden.

Although special education schools were present in the region, each school only accepted children with certain types of disabilities. Consequently, some caregivers had difficulty finding special education schools that specialized in their children's condition. Even when such schools are available, geographic inaccessibility prevents some caregivers from taking their children to school. Furthermore, other caregivers lacked information and were confused about the types of schools available to their children.

"I took my older son to M school, but I also asked the doctor if I could take my son to a school for ADD (attention deficit disorder) children. However, the doctor said that there was no such school in the area. There are schools for either physically disabled children or those with Down syndrome. I went to every place (in search of a school for ADD)". (No. 3)

*Vocational training.* Caregivers wanted their children to be accepted by society. They hoped that their children would secure appropriate jobs so that they could be self-re-



liant and live independently. They expected appropriate job opportunities and training for their children.

“I want G to have a job that suits her ability ... She cannot do farm work, and sometimes she is lazy; but, she can do Jeed drug work (tobacco leaf preparation)”. (No. 7)

## Domain 4: Social needs

*Support from the community.* In resource-limited settings, caregivers' primary source of support was close family members and relatives. Community members also supported caregivers in various ways, such as providing advice and encouragement, helping them access medical and welfare services, and providing affordable supervision of the children. However, some caregivers struggled to obtain appropriate support from their community.

“Never (received assistance). If we do not ask him (the village chief), he will not come. We were not interested in helping each other”. (No. 1)

*Ethical needs.* Living in a rural area where people are concerned about others in the community, caregivers mentioned experiencing prejudice and a lack of privacy. Some caregivers wanted to hide their children's disease and condition from other people; however, they were forced to resign themselves to being unable to conceal their situations.

“I used to hide it (the child's disease), but now there is no place to hide”. (No. 14)

“My family runs a small shop. People used to come to buy things, but they stopped coming after they heard that my child was sick”. (No. 15)

*Exchanges with peer caregivers.* Exchanges with other family members caring for children with similar conditions were helpful as they were an important source of information. They provided comfort and encouragement and deeply understood the feelings and experiences of caregivers.

## Domain 5: Information needs

*Easy access to necessary and appropriate information.* The caregivers needed information on four other domains. Although healthcare professionals explained the children's conditions to the caregivers, some caregivers were not content with these explanations and desired additional advice regarding better means of caring for their children. In particular, when caregivers felt that some advice was not appropriate for their children's specific condition, they sought alternative or further information. Caregivers needed information not only when they initially sought help for their children but also for daily problems throughout their care life.

“They (hospital staff) taught me [...], such as massaging her stomach or legs. I listened to them but did not do it... She vomits everything she eats. They taught me to massage her stomach and legs, which would not help her”. (No. 10)

## Discussion

This qualitative study documented and classified the needs of caregivers of children living with disabilities in resource-limited settings. The needs span five domains: health and medical, welfare, educational, social, and informational needs, consisting of a comprehensive needs assessment framework.

The WHO indicates that people with disabilities face widespread barriers in accessing services, including health-care, education, employment, and social services<sup>14</sup>. Our study identified the needs of caregivers per these barriers, and identified information needs as an independent domain intertwined with the other four domains.

Child disability affects not only the child but also their caregivers. Therefore, services for children with disabilities should address their caregivers' needs. However, previous studies on the needs of caregivers of children with disabilities were mainly conducted in high-income countries. For example, a scoping review of the supportive care needs of parents of a child with a rare disease included 29 studies, of which only two were conducted in resource-limited countries<sup>15</sup>. Furthermore, these studies have often been conducted in urban areas, reflecting relatively better access to resources. However, in resource-limited settings, caregiving requires more physical and psychosocial labor than in well-resourced settings. Our study is one of the few to focus on caregivers living in resource-limited settings.

The domain from which most categories were extracted was “Health and Medical Needs.” Caregivers' concerns focused on their children's health conditions, better treatment, and rehabilitation services. Previous studies on the needs of caregivers caring for children with disabilities have also focused on health needs, such as delayed and forgone care<sup>16</sup>, lack of preventive care<sup>17</sup>, and caregiver stress<sup>18</sup>.

However, a review<sup>15</sup> reported that the most cited needs were social needs, such as access to a support group and communication with other parents. This could be because the studies included in the review were mostly conducted in high-income countries. In well-resourced settings, basic health and medical support are fulfilled, and more social connections and inclusion become important. However, our study was conducted in resource-limited settings and service availability was low, resulting in an increased need for better medical and rehabilitation services.

In Thailand, health-promoting hospitals were placed within approximately 10,000 inhabitants; and community health nurses (CHNs) were employed<sup>19</sup>, who are key personnel in community health programs. Their activities are focused on health promotion and disease prevention, such as maternal and child health, prevention of lifestyle-related diseases, and infectious disease control. Currently, children with disabilities and chronic conditions are not a priority,

since the need for these children has shifted from medical treatment to welfare. However, caregivers still need timely health advice and fulfillment of other needs. Therefore, CHNs can serve as a hub to assign their needs to an appropriate sector and assist them in accessing it.

The second-largest need domain mentioned by caregivers was welfare. Financial support and care burden relief are common and often serious, unmet needs<sup>15, 20</sup>; however, the condition is worse in resource-limited settings. Difficulties in finding respite services and limited job opportunities in rural areas make finding a job compatible with childcare a challenge. Therefore, in our study area, some parents of children with disabilities migrated to cities to find work, leaving their children in care of their grandparents. This solves financial problems. However, grandparents raising grandchildren with disabilities are known to have elevated health risks<sup>21</sup>.

One of the most common expenses mentioned was transportation. The WHO noted that limited access to transportation frequently discourages people with disabilities from accessing health care<sup>9</sup>. This is especially true in resource-limited settings, where caregivers need to travel long distances to access an appropriate service, increasing not only transportation fees but also causing loss of income owing to the time taken off from work.

Educational needs are not a domain that healthcare professionals typically handle. However, in resource-limited settings, education is not only limited to the acquisition of knowledge and skills but also provides respite for caregivers while children are engaged in school. Therefore, it is necessary to have access to appropriate education. Teachers can also play an important role by training children with disabilities to be independent and adapt to society, eventually reducing caregivers' burden.

Some children with disabilities receive inclusive education in general schools. However, it is reported that approximately 30% of children with disabilities have either no education or have left school, especially after grade 5<sup>10</sup>.

The report also pointed out that the limited number of special schools in the area also prevents educational opportunities for children lacking appropriate education, owing to their conditions and severity. Our findings are consistent with those of this report. The caregivers mentioned that their children had to leave their respective general schools because learning information became challenging and was considered unsuitable for their children. They also mentioned that some types of special schools, such as those for children with autism spectrum disorder (ASD) and other developmental disorders, were unavailable in the area.

Training general school teachers to prepare for inclusive education, increasing the number and specialty of special schools or special classes in the area, and decreasing other barriers, such as transportation and educational expenses, are important measures for making education available to

all children with disabilities.

In Maha Sarakham, where community ties are strong, community members support caregivers in various ways. However, these strong ties sometimes lead to a lack of privacy. Therefore, ethical needs were identified as an important category in the social needs domain. In areas where there is a lack of public services, support from the community and peer caregivers is especially important. Healthcare professionals must intervene in the community to create an understanding and supportive environment. Self-help groups are also effective in resource-limited settings to empower caregivers through new skills, social connectedness, resource mobilization, and improved self-efficacy<sup>22</sup>.

Information needs appeared in all the four domains. Caregivers require detailed and continuous information about their children's diseases and available services. However, access to the necessary and appropriate information is often hindered in resource-limited settings. Hence, caregivers are deterred from timely access to needed support<sup>23</sup>.

For caregivers who have Internet access, web-based information is useful for providing up-to-date information specific to their children. However, in resource-limited settings, web information is often inaccessible to caregivers who have financial difficulties or are old. Therefore, a one-stop information center is useful when caregivers, including those who are old or have difficulty reading and writing, can access the necessary information covering all four domains with professional help.

## Limitations to the study

This study was conducted in a rural region in Thailand. Although the five targeted areas seem comprehensive, the findings may reflect the unique conditions in rural Thailand. Therefore, different socio-cultural contexts could raise unexplored categories. However, the framework developed in this study could serve as a starting template for assessing the needs of caregivers of children with disabilities living in resource-limited settings.

## Conclusions

This qualitative study revealed 19 needs of caregivers caring for children with disabilities in resource-limited settings across five major domains. Although the underlying disabilities of the children varied, their caregivers shared some common needs. As primary care providers, healthcare personnel serving an underprivileged population are often the first point of contact for caregivers. Healthcare personnel are responsible for the networking and coordination of limited and, therefore, valuable services for caregivers. We provide a conceptual framework that enables a comprehensive assessment and policy development for serving children with disabilities and their caregivers.

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## References

1. World Health Organization. WHO global disability action plan 2014–2021. Better health for all people with disability. Geneva: WHO; 2015. 1–8. <https://www.who.int/publications/i/item/who-global-disability-action-plan-2014-2021> (Accessed Sep. 14, 2021)
2. Kuper H, Heydt P. The Missing Billion. Access to health services for 1 billion people with disabilities. 2019. [https://static1.squarespace.com/static/5d79d3afbc2a705c96c5d2e5/t/5f284cb69af8a9396df3f81c/1596476607957/v3\\_TheMissingBillion\\_revised\\_0620.pdf](https://static1.squarespace.com/static/5d79d3afbc2a705c96c5d2e5/t/5f284cb69af8a9396df3f81c/1596476607957/v3_TheMissingBillion_revised_0620.pdf) (Accessed Sep. 14, 2021)
3. The Lancet. Prioritising disability in universal health coverage. *Lancet* 2019; 394: 187. [Medline] [CrossRef]
4. Kuper H, Monteath-van Dok A, Wing K, *et al.* The impact of disability on the lives of children; cross-sectional data including 8,900 children with disabilities and 898,834 children without disabilities across 30 countries. *PLoS One* 2014; 9: e107300. [Medline] [CrossRef]
5. Larson-Nath C, Goday P. Malnutrition in children with chronic disease. *Nutr Clin Pract* 2019; 34: 349–358. [Medline] [CrossRef]
6. Hartley S, Ojwang P, Baguwemu A, *et al.* How do carers of disabled children cope? The Ugandan perspective. *Child Care Health Dev* 2005; 31: 167–180. [Medline] [CrossRef]
7. Asa GA, Fauk NK, Ward PR, *et al.* The psychosocial and economic impacts on female caregivers and families caring for children with a disability in Belu District, Indonesia. *PLoS One* 2020; 15: e0240921. [Medline] [CrossRef]
8. Hendricks C, Lansford JE, Deater-Deckard K, *et al.* Associations between child disabilities and caregiver discipline and violence in low- and middle-income countries. *Child Dev* 2014; 85: 513–531. [Medline] [CrossRef]
9. World Health Organization, the World Bank. World Report on Disability. Geneva: WHO; 2011.
10. Faculty of Social Administration, Thammasat University, United Nations Children’s Fund (UNICEF) Final Report. Policy implementation analysis on disability grant of Thailand. New York: UNICEF; 2019. 9–15. <https://www.unicef.org/thailand/media/5511/file/Policy%20Implementation%20Analysis%20on%20Disability%20Grant%20of%20Thailand%20EN.pdf> (Accessed Feb. 14, 2022)
11. The Child and Adolescent Health Measurement Initiative (CAHMI) The Children with Special Health Care Needs (CSHCN) Screener<sup>®</sup>. <https://depts.washington.edu/dbpeds/Screening%20Tools/CSHCN-CAMHIScreener.pdf> (Accessed Sep. 30, 2021)
12. Maddocks S, Moodley K, Hanass-Hancock J, *et al.* Children living with HIV-related disabilities in a resource-poor community in South Africa: caregiver perceptions of caring and rehabilitation. *AIDS Care* 2020; 32: 471–479. [Medline] [CrossRef]
13. Maddocks S, Nakooda MZ, Cobbing S, *et al.* Perceptions of care and rehabilitation for children living with HIV in KwaZulu-Natal province, South Africa. *Vulnerable Child Youth Stud* 2020; 16.
14. World Health Organization. Overview of the global situation. IN WHO Global Disability Action Plan 2014–2021. Geneva: WHO; 2015.
15. Pelentsov LJ, Laws TA, Esterman AJ. The supportive care needs of parents caring for a child with a rare disease: a scoping review. *Disabil Health J* 2015; 8: 475–491. [Medline] [CrossRef]
16. Kerfeld CI, Hoffman JM, Ciol MA, *et al.* Delayed or forgone care and dissatisfaction with care for children with special health care needs: the role of perceived cultural competency of health care providers. *Matern Child Health J* 2011; 15: 487–496. [Medline] [CrossRef]
17. Chi DL, McManus BM, Carle AC. Caregiver burden and preventive dental care use for US children with special health care needs: a stratified analysis based on functional limitation. *Matern Child Health J* 2014; 18: 882–890. [Medline] [CrossRef]
18. Feizi A, Najmi B, Salesi A, *et al.* Parenting stress among mothers of children with different physical, mental, and psychological problems. *J Res Med Sci* 2014; 19: 145–152. [Medline]
19. Arakawa N, Ota K, Piyabanditkul L, *et al.* Construction and usability of community health nursing database in rural north-eastern Thailand. *Int Nurs Rev* 2018; 65: 515–523. [Medline] [CrossRef]
20. Parish SL, Shattuck PT, Rose RA. Financial burden of raising CSHCN: association with state policy choices. *Pediatrics* 2009; 124(Suppl 4): S435–S442. [Medline] [CrossRef]
21. Baker LA, Silverstein M. Depressive symptoms among grandparents raising grandchildren: the impact of participation in multiple roles. *J Intergenerational Relationships* 2008; 6: 285–304. [Medline] [CrossRef]
22. Bunning K, Gona JK, Newton CR, *et al.* Empowering self-help groups for caregivers of children with disabilities in Kilifi, Kenya: Impacts and their underlying mechanisms. *PLoS One* 2020; 15: e0229851. [Medline] [CrossRef]
23. Nuri RP, Ghahari S, Aldersey HM, *et al.* Exploring access to government-led support for children with disabilities in Bangladesh. *PLoS One* 2020; 15: e0235439. [Medline] [CrossRef]