



Caregiver voices in Cambodia: Supporting young children with disabilities to reach their full potential

Study Report

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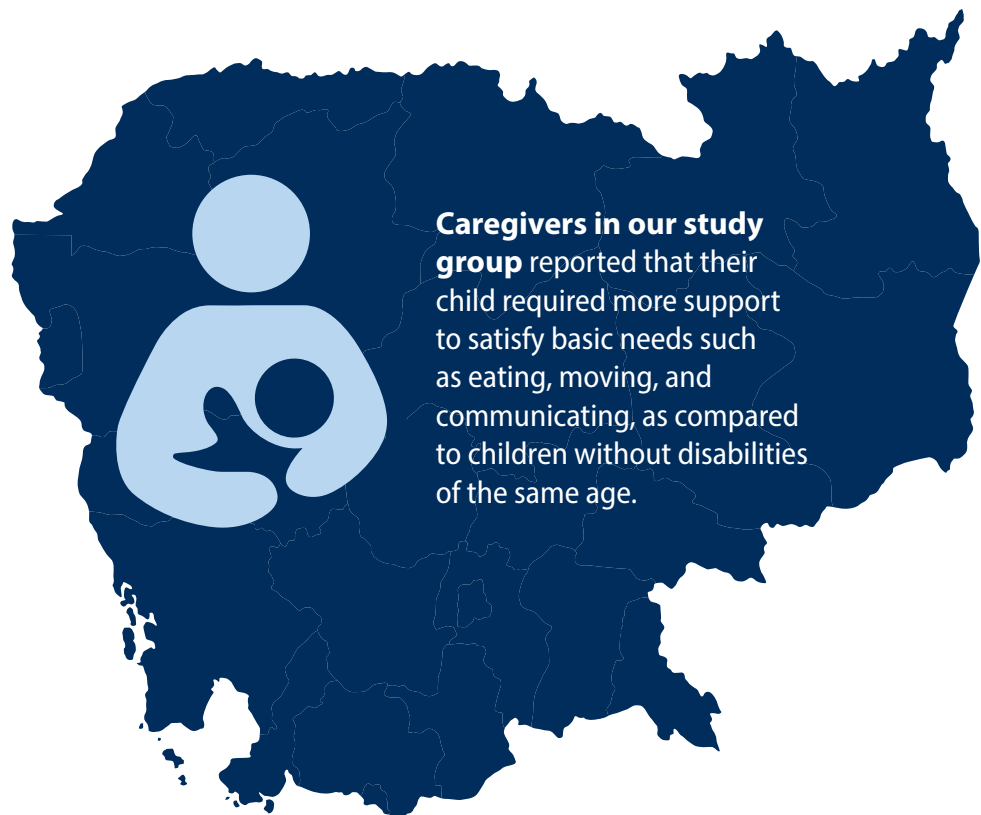
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Executive Summary

Young children with disabilities require extra time and resources to ensure that they are able to reach their full developmental potential. In order to explore (1) how caregivers of young children with disabilities provide nurturing care (World Health Organization [WHO], 2018), (2) the challenges such caregivers face in accessing necessary resources for their children, and (3) caregivers' resilience in the face of those challenges, members of RTI's Center for Thriving Children and the Cambodia Physical Therapy Association conducted a study among caregivers of children under five with disabilities in Cambodia. The study, entitled "Reaching Their Full Potential," involved a convenience sample of 58 surveys with caregivers of children under five with a disability, matched with a comparison group of 58 caregivers of children under five without a disability. The team also completed in-depth interviews with a subset of 15 of the caregivers of children with disabilities, as well as 11 key informant interviews with service providers.

Caregivers of young children with disabilities reported excess stress and strain. Caring for a child with a disability both impacted the household's ability to earn income and created additional financial needs, e.g., paying for additional medical services. For instance, caregivers in our study group reported that their child required more support to satisfy basic needs such as eating, moving, and communicating, as compared to children without disabilities of the same age. Many caregivers of children with disabilities reported difficulties with feeding their child. Financial strain was reported by nearly every caregiver of a child with a disability; nearly two thirds of respondents said that their family had faced quite a bit or very much financial strain as a result of their child's disability. Additionally, socioemotional support within the community varied; one third of caregivers who participated in in-depth interviews reported that community members had encouraged them to leave their child with a disability at an orphanage or not spend time or resources on the child.



Remarkably, despite these myriad challenges, caregivers of children with disabilities provided nurturing care similarly to caregivers of children without disabilities, implemented admirable coping strategies, and even reported high levels of both self-efficacy and enjoyment of their child. Almost all had found numerous coping strategies and, in interviews with caregivers, most expressed determination to continue caring for their child, sometimes despite advice to the contrary from community members. Caregivers of children with disabilities reported practices in responsive care and early learning (e.g., singing songs, playing) that were similar to those of caregivers of children without disabilities. Almost three fourths of caregivers of children with disabilities reported that they enjoyed spending time with their child quite a bit or very much. They commonly reported seeking and receiving advice or help from others, taking action to try to make their situations better, and trying to come up with strategies to improve their situation. Equally important, caregivers of children with disabilities expressed high levels of self-efficacy. Nearly all reported they could always manage to solve difficult problems, could deal with unexpected events, could find solutions to problems, and could handle whatever came their way.

The caregivers' love for their children, along with their resilience and self-efficacy, represent unparalleled existing resources for this population. Through effective public programs and policies, young children with disabilities and their families can be more fully supported to reach their full potential. This report concludes with several policy recommendations. These recommendations address public resources across sectors in Cambodia, including social protection services, considerations for health system strengthening and workforce development, and engagement of caregivers as key stakeholders in policies and programs related to nurturing care of young children with disabilities.

Background and Objectives

Laudable improvements have been made in child mortality in recent decades, and the global community has rightly expanded its focus to helping children not only to survive but also to thrive. However, to ensure equitable improvements in child outcomes and to address the needs and rights of all children, a focus is needed on modalities to support children with disabilities. Across low- and middle-income countries around the world, children with disabilities are more likely to live in poverty and are less likely to be enrolled in school, even controlling for other factors such as gender, economic status, or rural living (Filmer, 2008).

In order to break this cycle of poverty and low educational attainment, caregivers need consistent access to the services and resources that allow them to best support their child. Gaining access to these resources, and improving their ability to provide their child with the five components of the Nurturing Care Framework—good health, adequate nutrition, responsive caregiving, safety and security, and opportunities for early learning (WHO, 2018)—set the child up for success. However, the literature is limited in the context of low- and middle-income countries and often focuses only on a particular disability.

Fundamental to families' and caregivers' ability to provide nurturing care are effective public programs, made available by appropriate national policies, coordination across government sectors and levels, and allocated resources. Indeed, the Nurturing Care Framework specifies that countries' governments need to lead and coordinate each of the strategic actions required to implement nurturing care.

Cambodia ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2012; the CRPD sets out general obligations for states to promote and protect the human rights of all persons with disabilities, including women and children. Although Cambodia's ratification of this Convention represents an important step forward, barriers to accessing basic education, health care, and transportation services still exist within Cambodia (Cordier, 2014). Additionally, these policies, especially in rural areas, are not being uniformly enacted (Wilbur et al., 2022). A 2021 assessment of access to health care and social services for people with disabilities in Cambodia highlighted the creation of the Government's Identification of Poor Households Program, but the absence of disability as a risk for poverty remains to be addressed.



Additionally, the key barriers to services were listed as lack of financial resources, low quality of care, lack of knowledge of social rights, social stigma, and geography challenges (Harder & Wendt, 2021).

As an independent, nonprofit research institute dedicated to improving the human condition, each year, RTI International funds small studies proposed by its staff. In Fiscal Year 2023, members of RTI's Center for Thriving Children carried out the Reaching Their Full Potential study in partnership with the Cambodia Physical Therapy Association.

The objectives of the Reaching Their Full Potential study were:

- To further global knowledge about the interventions that best support caregivers, families, and communities in optimizing outcomes and facilitating full inclusion for young children with disabilities and their families.
- To better understand the experiences of families with children with disabilities, their level of resilience, and their needs.
- To understand how the components of nurturing care (health care, nutrition, responsive caregiving, security and safety, and opportunities for early learning) are used or adapted by families with children with disabilities to support their children.



Methods

The Reaching Their Full Potential study was a mixed methods study utilizing a quantitative survey, qualitative in-depth interviews, and qualitative key informant interviews. The team identified a convenience sample of caregivers of children with disabilities identified through project implementation of the United States Agency for International Development's (USAID's) Cambodia Integrated Early Childhood Development (IECD) Activity (2020–2025) in Kampong Thom and Preah Vihear provinces. We created a comparison group of caregivers from a pre-existing population-level dataset of caregivers of children under five in IECD implementation areas, who had already completed a survey including topics such as caregiver-reported nurturing care behaviors, feeding and nutrition practices, and gender roles and division of labor among caregivers. The comparison group matched caregivers in the study group based on location, child age, and other caregiver demographic variables such as literacy, education level, and employment type.

We first completed a desk review to identify gaps in knowledge and validated data collection tools related to the study areas of interest. We conducted a quantitative survey with the study group, along with in-depth interviews with a sub-set of those caregivers of children with disabilities who completed the quantitative study. We also conducted key informant interviews with local service providers and stakeholders. Data collection by trained enumerators and interviewers took place in July and August, 2023.



Data collection instruments



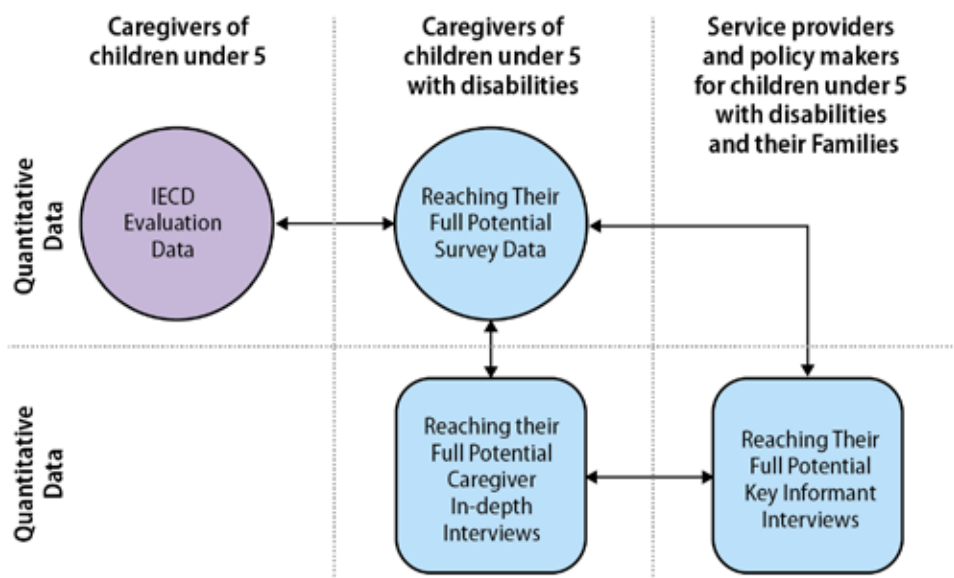
- The quantitative survey administered to the study group (caregivers of children with disabilities) was similar to the survey already completed by the comparison group, but included additional questions about caregiver resilience, mental health, and additional stresses associated with their child's disability.
- The qualitative in-depth interview guide included topics such as caregiver experiences supporting their child with a disability, impacts of the child's disability on family life, social stigma, supports they receive as caregivers, their needs, and their coping methods.
- The structured key informant interview guide included questions about the services available to families with children with disabilities, those families' needs, community perceptions of those families, and social safety nets.

To analyze the quantitative data, the study team conducted descriptive analyses comparing responses from caregivers of children with disabilities to responses from the comparison group of caregivers of children without disabilities. For questions that were administered only to the caregivers of children with disabilities, descriptive analyses were performed without a comparison group. The study team created codebooks, then coded and created thematic memos to analyze the in-depth interviews and key informant interviews. When available, data from all three types of data collection was triangulated to draw conclusions.

The study received ethical approval from the Cambodia National Ethics Committee for Health Research in July 2023 and data collection took place by trained enumerators in July and August of 2023.

The data components used in the study are shown in [Figure 1](#)

Figure 1. Reaching Their Full Potential study: Data components



Results

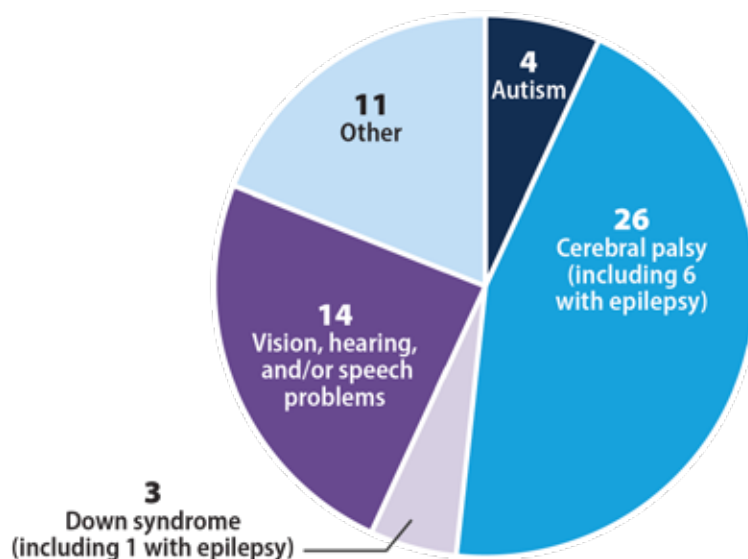
Overall, the study team completed 58 surveys with caregivers of children under five with disabilities, which constituted the study group. We created a matched comparison group with 58 caregivers of children under five without a disability. The study team also completed 15 IDIs with a subset of the 58 caregivers of children with a disability, and 11 key informant interviews with service providers at various levels of the public sector, representatives of nongovernmental organizations (NGOs), and national-level stakeholders.

Demographics

Sixty-seven percent of caregivers in both the study and comparison groups for the quantitative survey lived in Kampong Thom Province, with the remaining 33% in Preah Vihear. All caregivers in the study group, and all but two in the comparison group, were female. About half in both groups could read and write, while 43% could neither read nor write. The majority of caregivers in both groups had primary education or less. Most stayed at home or were farmers. Given the matching process used to create the comparison group, the demographics of caregivers and children in the study and comparison groups were similar.

The majority of children whose caregivers participated in the survey were between two and five years old. Child sex was not part of the matching process; in the study group, 69% were male and 31% female while the comparison group was evenly split (50% male, 50% female). The children were diagnosed with a variety of disabilities, as shown in [Figure 2](#). The most common disability among the group was cerebral palsy, with an additional 14 children living with vision, hearing, and/or speech problems (which could not be fully addressed by surgery or adaptive devices). Disabilities accounted for in the “Other” category included cleft lip and palate, club foot, hydrocephalus, microcephaly, and others. Seven children in the sample had epilepsy in addition to other conditions

Figure 2. Diagnoses of children whose caregivers were in the study group



Eight of the 11 key informants worked in public health care delivery (three midwives; two nurses, one of whom also was a health center director; one doctor; and two provincial-level health care facility directors). Two key informants worked at NGOs active in the disability sector in Cambodia. One key informant was from the Ministry of Sport, Veterans Affairs, and Youth Rehabilitation (MoSVY), which was responsible for disability services in Cambodia at the time of data collection.

Caregiver Challenges

Caregivers of children with disabilities reported many challenges they and their families face because of their child's disability. These ranged from the additional time and effort required to care for a child with a disability and challenges feeding their child, to financial strain and emotional stress.



Caring is [very] difficult, [he] cannot sit.... We have to carry him all the time [if] we want to take him out of bed. Also, have to change [his] position. He cannot roll by himself.

—35-year-old mother of child with cerebral palsy

Financial strain

Financial strain was reported by nearly every caregiver of a child with a disability. Only one caregiver (out of 58) reported that their household was always able to meet regular and unexpected financial demands. Ninety-five percent of households in the sample had no financial savings. Over 60% of caregivers of a young child with a disability said that their family had faced quite a bit or very much financial strain as a result of their child's developmental challenge or disability.

Caring for a child with a disability both impacted the household's ability to earn income and created additional financial needs such as paying for additional medical services. Two thirds of caregivers who participated in IDIs reported that their ability to earn income was impacted by caring for their child with a disability, and over half said they could not afford health care services, medication, or transportation to access services for their child (in the absence of support from the IECD project). Several reported having to borrow money from family members or beg pharmacies to give them medication up front, and then not being able to repay their debts.

"When he gets sick, and I do not have money to pay for taking him to the hospital, I do not know how to do it. If my mum has money, I borrow [from] her. If not, I go to market to buy medicine and ask them to pay back later when I can.

—40-year-old mother of child with autism

Don't have money. Have to borrow [from] other[s]. Not easy, most of the time they do not give. If they have, [I] have to pay them back. I don't have money to pay them. They get angry.

—31-year-old mother of child with cerebral palsy



This problem affects mainly on our income generation, and we spend a lot of money for taking care of him... There is no other choice rather than taking him to work with me. And when he is sick, just take him to hospital. But sometimes both of us cannot go to work too because we are too worried about him."

—27-year-old mother of child with autism and seizures

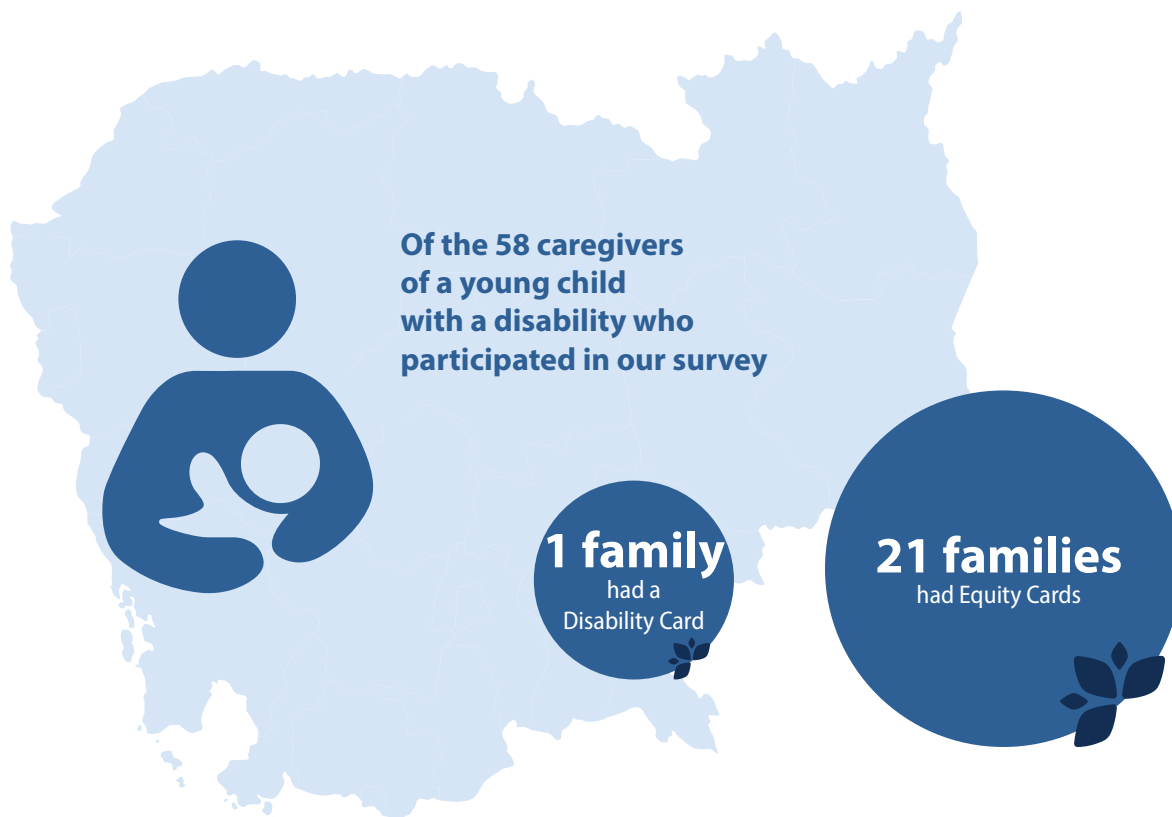


When his dad goes to work away, I cannot take good care of my child alone. If [he gets a] fever, [I] call his dad to come back."

—22-year-old mother of a child with cerebral palsy

Caregivers noted that many specialized services are located far from their homes, and the costs of transportation to and from the facility, and eating outside of the home, are barriers to receiving care. Key informants also mentioned that many families live far from services, such that the cost of transport, or the opportunity cost of missing a day or more of work, make it hard for them to seek care, even for more typical illnesses or needs.

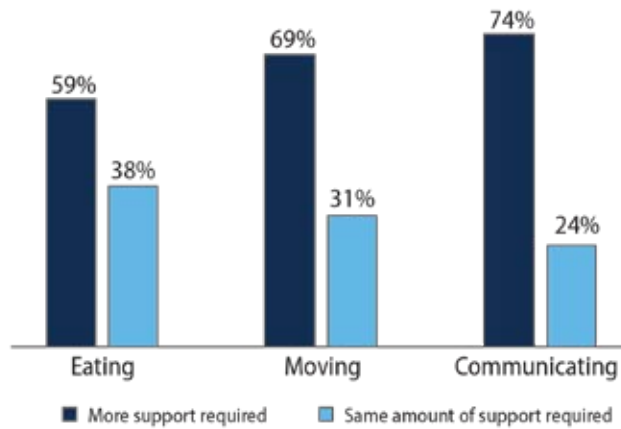
Furthermore, caregivers reported low levels of participation in social protection programs. Of the 58 caregivers of a young child with a disability who participated in our survey, only one family had a disability card, and about one third (21 families in total) had an Equity Card, despite the overwhelming financial strain these households faced.



Caregiving requires more time and additional work

Caregivers in the study group reported that their child required more support to satisfy basic needs such as eating, moving, and communicating, as compared to typically developing children of the same age (Figure 3). In qualitative interviews, caregivers elaborated on the burden this causes. Some spoke about never being able to put their child down or take their eyes off their child for even a minute. Others described having to wash blankets and clothing several times a day because they were unable to afford diapers and their child could not communicate or control when they needed to toilet.

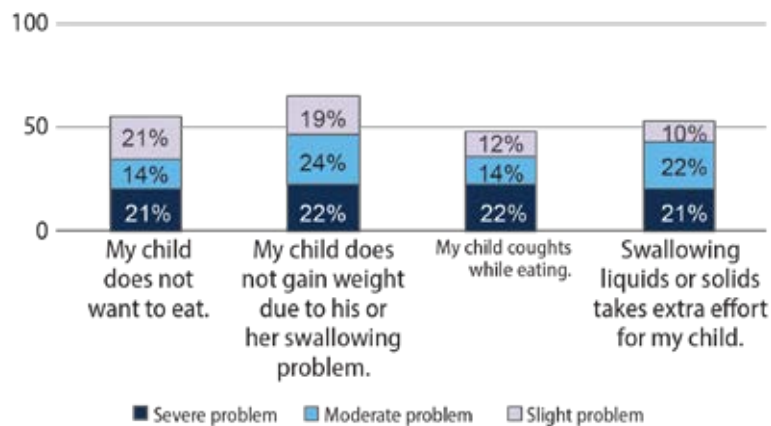
Figure 3. Support required for basic functions as compared to children of a similar age without a disability



Feeding challenges

Challenges feeding their child with a disability were common among participants (see Figure 4). Children not gaining weight because of swallowing issues was reported as a problem by 65% of caregivers, while 55% said their child not wanting to eat was a problem, and 53% said the extra effort required for their child to swallow was a problem. In interviews, caregivers described various adaptations to get their children to eat. Some said that their children could only eat very specific food items that took extra time to prepare, such as rice boiled until very soft and then blended or smashed until smooth to prevent choking. Some described holding their children in specific ways to avoid choking, or only feeding their child very small amounts and over long periods of time.

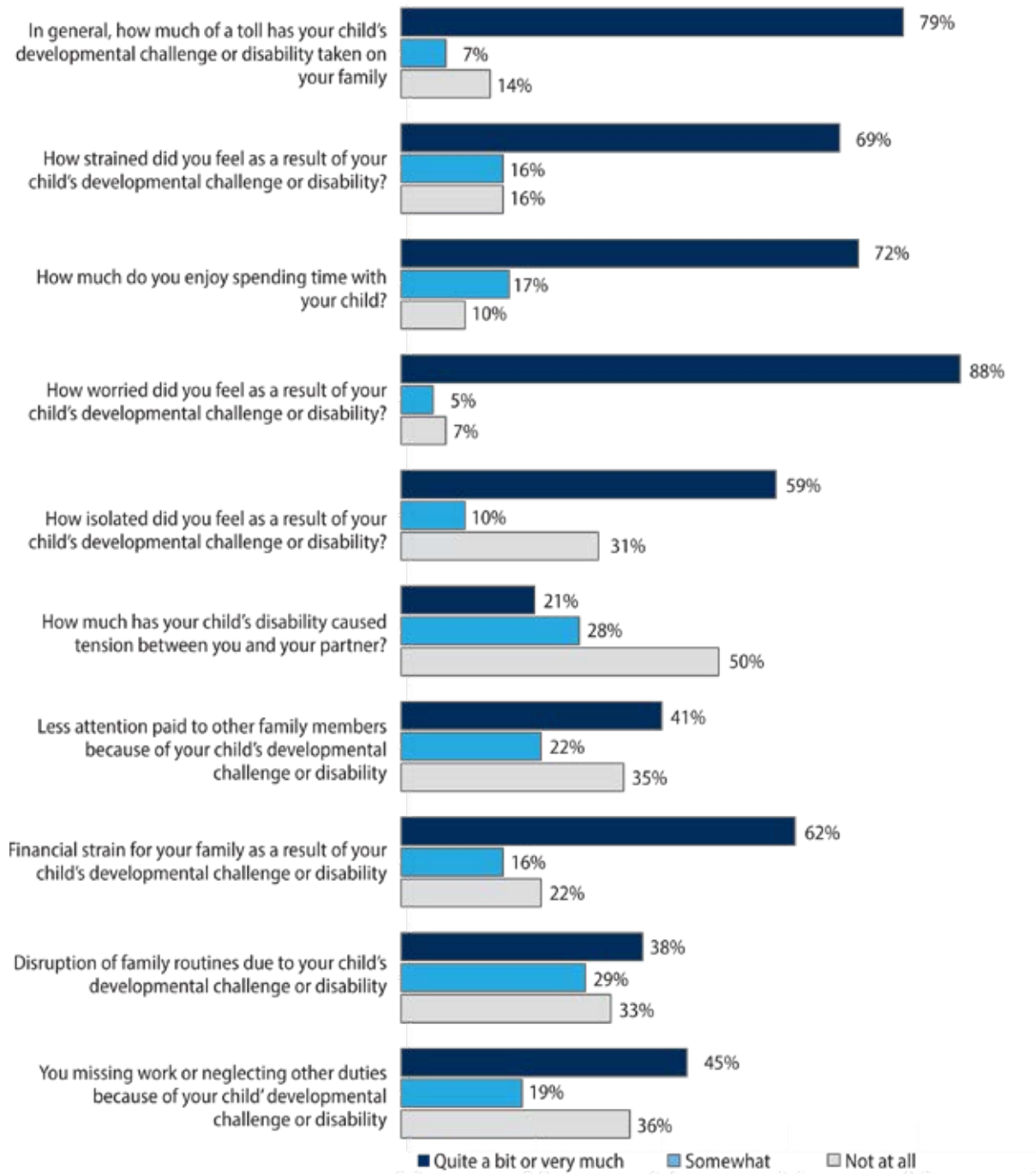
Figure 4. Severity of feeding challenges, as reported by the caregiver



Compounding stresses and little respite

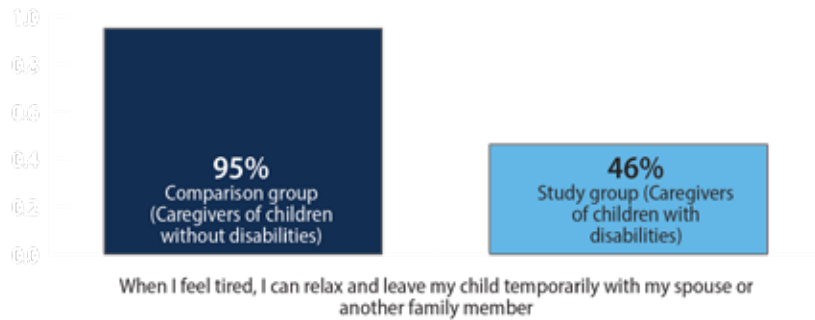
In addition to financial strain, caregivers of young children with disabilities reported high levels of emotional stress and other strains on their families. As shown *Figure 5* below, many caregivers felt that worry (88%) and isolation (59%) caused by their child's disability were "quite a bit" or "very much" a problem. Nearly 80% felt that their child's disability had taken a severe toll on their family. Nearly half reported that their child's disability had caused tension between themselves and their partners.

Figure 5. Compounding stresses



Many caregivers of a child with a disability reported feeling “always on duty.” When asked whether they agreed with the statement “When I feel tired, I can relax and leave my child temporarily with my spouse or another family member,” fewer than half of study caregivers reported that they could, compared with almost all of those in the comparison group (Figure 6).

Figure 6. Caregivers’ assessment of respite care



Community Reactions

The study team gathered information about community reactions to children with disabilities and their families through qualitative interviews. Participants described having a wide variety of experiences when interacting with community members. A third of IDI respondents reported that community members had encouraged them to leave their child with a disability at an orphanage or not spend time or effort on the child. However, several others said they received encouragement to continue caring for their child from community members. Some said that others in their community avoid interacting with them because they worry about their own child being affected somehow, or they considered the family unhygienic. Other respondents stated that community members had nothing positive or supportive to say, even if they were not outright unsupportive.

A few key informants working at health centers echoed concerns about discrimination or lack of community support for children with disabilities and their families, although one felt it was not a major problem.



[I] do not have supporting people, only those who ask me to abandon [my child]. They said, ‘Stop caring [for] him, caring for 3-4 year[s] and still [he’s] not cure[d]. Take him to an orphanage.’

—34-year-old mother of a child with cerebral palsy



Services

Caregivers recognized the importance of access to specialized medical care and rehabilitative therapies to help their children improve. As expected due to the sampling frame, the vast majority of respondents (93%) reported receiving support from the IECD Activity to access care for their child related specifically to the child's disability. Of these, 63% said they would not be able to afford the same specialized care without support from the project. Key informants also spoke about the challenges families face when accessing even general health care, including lack of money and the time required to travel to health facilities. They also explained that specialized care is not widely available in local or provincial facilities, so families have to travel to facilities in other provinces, such as Angkor Hospital for Children in Siem Reap or Kantha Bopha Children's Hospital in Phnom Penh, for certain medications or appropriate services.

Resilience and Coping

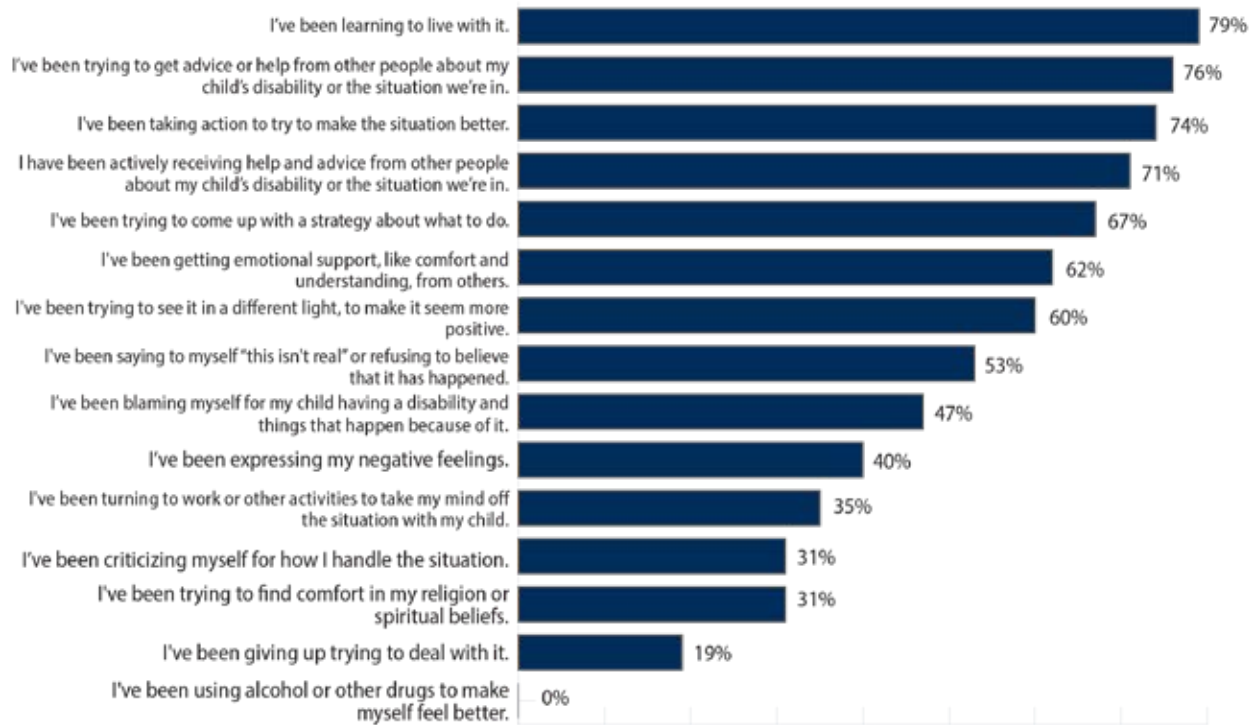
Despite these myriad challenges, 89% of caregivers of young children with disabilities reported that they enjoyed spending time with their child. In IDIs, caregivers expressed determination to continue caring for their children with disabilities. Through the quantitative survey, caregivers reported utilizing numerous coping strategies (Figure 7). Apart from learning to live with the situation, caregivers commonly reported seeking and receiving advice or help from others (76% and 71% respectively), and taking action to try to make the situation better (74%). Critically, two-thirds (67%) said they are actively trying to come up with strategies to improve their situation. Although nearly half (47%) reported blaming themselves for having a child with a disability, fewer than 20% reported giving up trying to deal with the situation, and none reported using drugs or alcohol as coping mechanisms.

They say, 'Don't take care of [your daughter] because of her problem.' ...Some say, 'How long [can she] survive.' I responded that she is my daughter, if I am poor or [it is] difficult, I have to care for her... I don't care... What they say [is] up to them."

—35-year-old mother of child with cerebral palsy

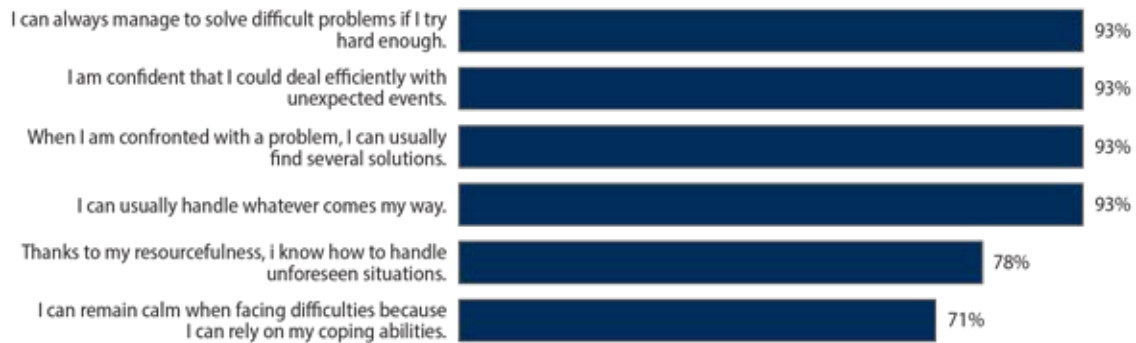


Figure 7. Coping strategies: Percentage of caregivers of children with disabilities using each coping strategy “a medium amount” or “a lot”



Equally importantly, caregivers expressed high levels of self-efficacy, as shown in [Figure 8](#). Nearly all reported they could always manage to solve difficult problems, could deal with unexpected events, could find solutions to problems, and could handle whatever came their way.

Figure 8. Caregivers of children with disabilities reporting that a statement is “moderately” or “exactly” true



Nurturing Care Behaviors

Caregivers of children with disabilities reported practices in responsive care and early learning (e.g., singing songs, playing) that were similar to those used by caregivers of children without disabilities. Specific indicators are shown in *Figures 9–12*. The family care indicators (*Figure 9*) came from a validated tool, while the responsive care (*Figures 10, 11*) and safety and security indicators (*Figure 12*) were developed by the IECD Activity to measure key behaviors. Comparisons are descriptive only, because the sample was not large enough to determine statistical significance.

Figure 9. Family care indicators: Percentage of caregivers who reported doing each activity in the previous 3 days

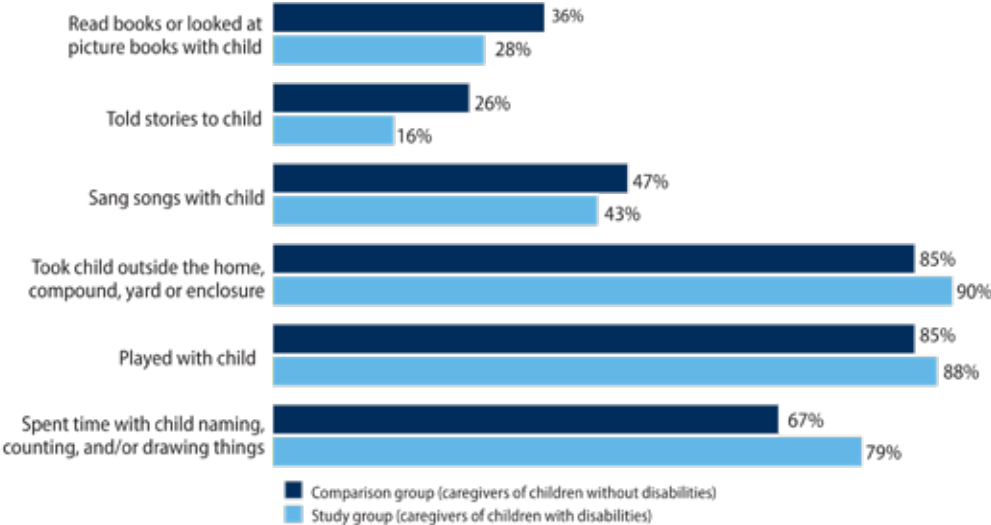
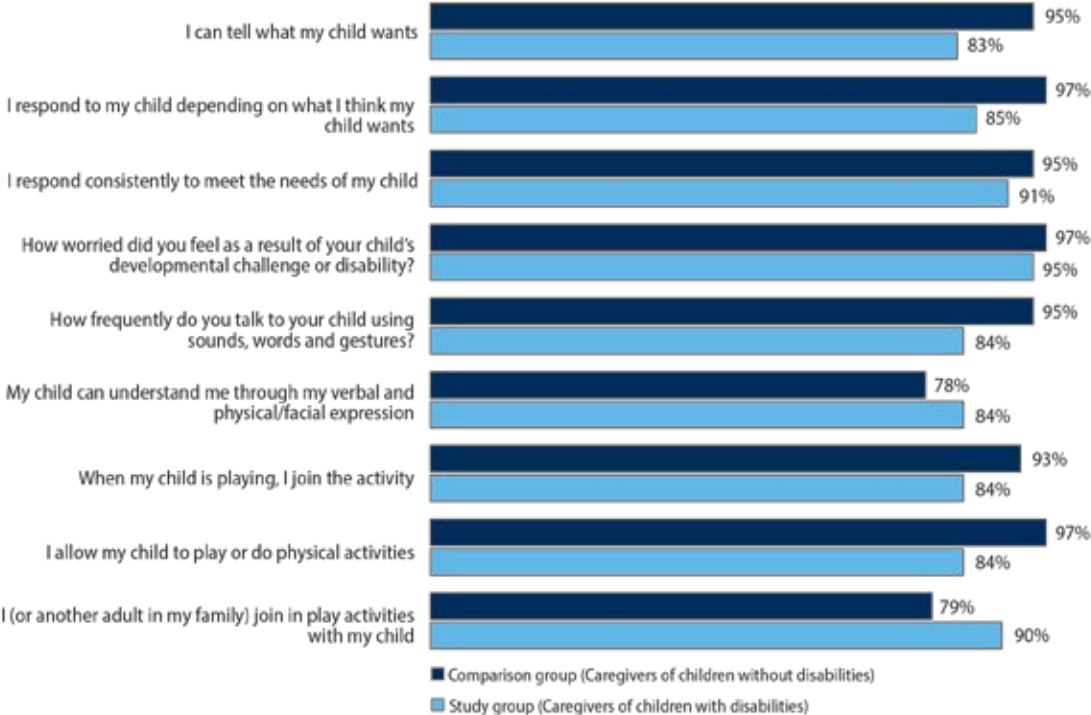
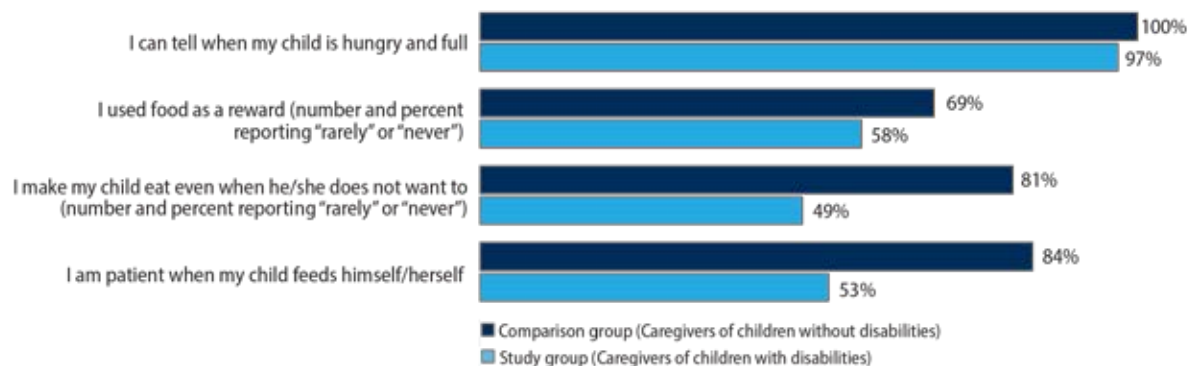


Figure 10. Responsive care – early learning: Percentage of caregivers responding “usually” or “some of the time”



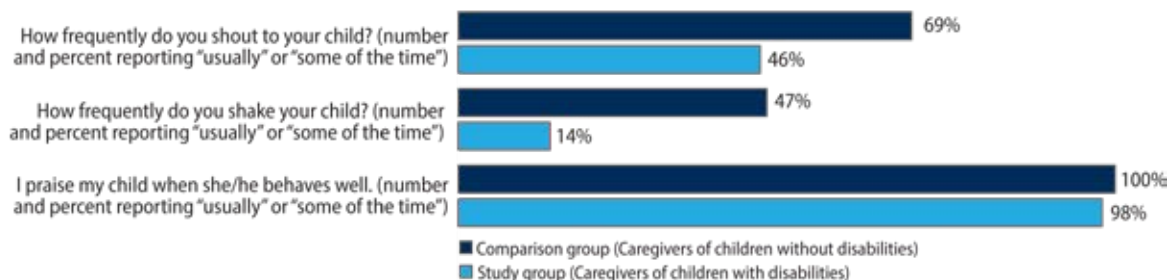
Caregivers of children with disabilities reported lower levels of using food as a reward or forcing their child to eat when they were not hungry, but also had less patience for their children feeding themselves (Figure 11).

Figure 11. Responsive care—feeding behaviors: Percentage of caregivers reporting each activity “usually” or “some of the time”



One point of difference in nurturing care behaviors between the two groups came in the realm of safety and security indicators (Figure 12). Caregivers of children with disabilities reported similar levels of praising their child, but much lower levels of shaking or shouting at their child as compared to caregivers of children without disabilities.

Figure 12. Safety and security indicators



Recommendations for Policy and Practice

The following recommendations stem from conversations with Cambodian and international experts and stakeholders about the study findings and their knowledge of the current context of disability and rehabilitation services in the country.

Social Protection Services

Recommendation: Streamline the application processes for social protection programs so that eligible families will be able to enroll in relevant programs in a timely manner. This change would facilitate timely uptake of necessary services and optimize children’s developmental outcomes. Also, optimizing the transparency of the process would allow caregivers to plan accordingly.

Recommendation: Make free health insurance available for families of children with disabilities. Insurance programs allow families to access primary and specialty health services at local, provincial, and regional levels. Insurance should also cover the full cost of medications and medical supplies prescribed by health care providers.

Progress to date:

- Children with disabilities are, by law, eligible for free health care with a government-issued disability or equity card.
- Under MoSVYV, rehabilitation services provided by the government are free of charge.

Gaps remaining:

- Many eligible children are not enrolled in the program or have not received the appropriate card.
- No comprehensive policy covering health insurance for children exists.

Recommendation: Provide financial support to families when they are required to travel for care for specialty services (transport and lodging).

Progress to date:

- Patients are entitled to small transportation and food stipends while receiving services.

Gaps remaining:

- Most rehabilitation centers no longer provide this stipend because no accommodations or cafeteria services are available.
- The existing stipends are well below actual costs associated with traveling to receive rehabilitation services.
- Additional financial support is necessary to allow families to access care, e.g., specialty care requiring travel.



Recommendation: Provide financial support (e.g., cash transfers) as income replacement to families of children with disabilities to cover excess caregiving responsibilities and encourage family care rather than institutionalization.

Progress to date:

- The Royal Government of Cambodia (RGC) has established a social support program through which communities identify households who are experiencing or at risk of poverty; eligible households receive an Equity Card, which entitles them to benefits including cash transfers. Eligibility criteria include having a family member with a disability.

Gaps remaining:

- Many households that might be eligible are not enrolled.

Capacity of Health Care System and Workforce

Recommendation: Strengthen referral system among health disciplines, e.g., primary to specialty care and allied services (therapies), with primary care as the central node.

Recommendation: With the WHO Rehabilitation 2030 Initiative as a reference, the RGC should articulate a strategic plan for professionalizing the key disciplines required to address the needs of people with disabilities, particularly children with disabilities. Such disciplines include, among others, physiotherapy, speech and language pathology/therapy, occupational therapy, and clinical nutrition (dietetics). Other allied health professionals essential for people with disabilities include prosthetists/orthotists. Funding for this strengthening will be essential.

Progress to date:

- The RGC is transitioning responsibility for rehabilitation services from the Ministry of Social Affairs, Veterans, and Youth (MoSVY) to the Ministry of Health (MOH), thereby integrating clinical services for persons with disabilities within the health sector.
- A National Strategic Plan on Disabilities 2024–2028 (MoSVY) is in draft form.
- A Strategic Plan on Disabilities in the Health Sector is in the consultation phase.
- The national Complementary Package of Activities (CPA), which sets standards for services at the level of referral hospitals, and the Minimum Package of Activities (MPA), which sets standards for services at Health Centers, are in the process of being revised and will include some rehabilitation services.

Gaps remaining:

- The transition of responsibility for delivering rehabilitation services from MoSVY to MOH remains a work in progress.
- Strategic plans for standardizing approaches to address disability issues have not yet been crafted.
- Although the CPA and MPA represent steps forward, in reality, very few rehabilitation professionals are available to work in these settings.
- The supply of health professionals (e.g., physical therapists, occupational therapists, speech–language pathologists) is low or nonexistent. Moreover, programs for training relevant professionals are few or nonexistent, or they are expensive relative to other professional training programs, and scholarships are not available.



Recommendation: Monitor implementation of services, where delivered, to identify opportunities for improving the quality of service delivery, and provide additional staff, training, on-the-job coaching, and other resources to ensure improvement.

Progress to date:

- The draft National Disability Strategy includes indicators of service.

Gaps remaining:

- First, services must be established, and then tools should be developed to collect effective and reliable data for regular improvement.

Recommendation: Provide sensitization training to health care workers (pre-service or in-service) related to caring for adults and children with disabilities—not only those with physical disabilities but also those with non-visible disabilities.

Progress to date:

- The RGC recently produced a guideline on mental health care.

Gaps remaining:

- Some services, e.g., for autism or mental health, are sparse in the country; a need exists for developing the workforce within relevant fields.

Recommendation: Develop a supply chain of assistive and adaptive devices and technologies, in collaboration with the relevant disciplines (prosthetists/orthotists, etc.).

Progress to date:

- Caregivers of children with disabilities reported many challenges they and their families face because of their child's disability. These ranged from the additional time and effort required to care for a child with a disability and challenges feeding their child, to financial strain and emotional stress. Financial Strain.

Gaps remaining:

- Rehabilitation and disability services are not available at most health centers.



Support to and Engagement of Caregivers

Recommendation: Engage caregivers of children with disabilities in national and subnational planning, budgeting, and training related to disability rights, as well as in health system strengthening and social protection services.

Recommendation: Support platforms (e.g., in-person and virtual support networks, disabled people's organizations, etc.) by which caregivers can be connected with others in similar situations to share knowledge, ideas, and resources.

Recommendation: Strengthen the capacity and sensitization of community leaders, including at the village, commune, and district levels, about ways they can support families of children with disabilities, including addressing stigma, streamlining the eligibility/enrollment process for relevant social protection programs, and galvanizing community support.

Progress to date:

- Previously, such outreach was implemented by government entities with the support of international funding; Village Health Support Group members and community members called Core Parents helped to mobilize this support.
- Transition of rehabilitation services to the MoH may promote engagement of stakeholders at the community level (i.e., through health centers or community programs)

Gaps remaining:

- Since international funding has largely evaporated, such sensitization activities are not often undertaken (outside of the USAID IECD Activity).



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