

ORIGINAL ARTICLES

**CHILDREN WITH DISABILITIES IN RURAL CAMBODIA:
AN EXAMINATION OF FUNCTIONAL STATUS AND
IMPLICATIONS FOR SERVICE DELIVERY**

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ABSTRACT

This study was conducted to obtain a clearer understanding of the functional status of children in rural Cambodia with disabilities, and to learn how families perceived and used relevant services for their children. Using existing databases, a survey was conducted targeting caregivers of 500 identified children with different types of disabilities, in two rural Cambodian provinces. Although 25% of the children with disabilities had difficulty seeing, almost none wore glasses. 42% of the children had difficulty with movement, but only half of that group used a mobility aid. Parents also reported that many children had trouble hearing, speaking, understanding, playing or talking to others, learning at school, remembering or concentrating on tasks, and holding or using objects. Many children had difficulty with activities because of emotional problems (53%) or pain (42%). Of the school-aged children, 55% had attended some school, and most of them had only attended one or two grades.

Some needed services and equipment are available but not always used by families, and other needed resources are currently unavailable. Barriers that need to be overcome are both informational and practical (e.g. financial) in nature. Strategies to meet needs should include assertive outreach, a coordinated mix of public and private providers, and greater involvement of families in problem-solving and decision-making.

INTRODUCTION

Cambodia

The disability prevalence rate in Cambodia is estimated at 4.7% of the population (1), meaning that more than half a million Cambodians have a disability. Because Cambodia has a very

young population, almost half of those with disabilities are under 20 years of age. This is a matter of concern because early disability can have a negative impact on school attendance, quality of life and productivity for many years to come.

In Cambodia, factors that may put children at particular risk for disability include lack of antenatal care or skilled delivery assistance for pregnant women (which can lead to congenital conditions), as well as serious childhood illnesses (e.g. acute respiratory illness, fever and diarrhoea) that are often untreated by trained health providers (2). Vaccination rates are still low for poor children, and analyses of height and weight measurements indicate that many children are stunted or underweight (2). Cambodia still has a high infant and early childhood mortality rate as compared to the rest of the region (3), suggesting that young children are quite vulnerable to disease and injury.

It has been reported that children with disabilities in Cambodia are less likely to attend school than their non-disabled peers because their disabilities require special services (e.g. accommodations for vision and hearing impairments) that are typically not available in Cambodian schools (1). Stigma and discrimination also appear to play a role in keeping children out of school (4, 5).

Purpose of the study

Handicap International Belgium (HIB) has been involved for more than two decades in rehabilitation efforts in Cambodia, and initially, most of the clients were adults who had experienced landmine accidents. However, over time, the population seeking rehabilitation services has shifted, with many children now coming for services, particularly those with developmental disabilities such as cerebral palsy (6). In order to better provide relevant services, and also to explore possible avenues for secondary prevention efforts, HIB felt the need to have a better understanding of the impairments and functional status of children with disabilities. Thus, a survey of 500 households was undertaken in the rural provinces of Siem Reap and Takeo, where there was a child with a disability. These provinces were chosen because they are areas of the country where HIB currently has active rehabilitation centres.

METHOD

Questionnaire development

The authors wanted to know about the children's body function and structure impairments, activity limitations and participation restrictions as described in the International Classification of Functioning, Disability and Health [ICF] (7), in order to obtain a better understanding of how the children were currently functioning in everyday life. Impairments, activity limitations and participation restrictions seem to be understood as aspects of disability in other developing countries as well (8). It was felt that the questionnaires directly tied to the ICF including the World Health Organisation Disability Assessment Schedule, or WHO DAS II (9) and WHO/UNESCAP Disability Questionnaire Version A (10), seemed more directed to adults than children, although they are meant to cover all age groups. Using the Washington Group Question Set (11) was also considered, but it did not ask an adequate range of questions for the study purpose. The Ten Question Questionnaire (12) focused on children, but it used a dichotomous scoring system (yes-no), whilst a scalable scoring system that would allow different thresholds for service provision decision-making was felt to be more appropriate for the study (13,14).

The authors also wanted to know what caused the disability, how the family had used the health system, and how they perceived the services they had used. In the end it was decided that none of the existing instruments were sufficient to obtain the data that were wanted, but some questions from all of them were used in the final questionnaire as well as suggestions from multiple individuals and organisations including disabled people's organisations and non-governmental organisations. The intended respondent was typically an adult, who was the parent or significant caregiver of the child with the disability. Questionnaire development, translation, pilot testing, revisions, final field testing and data collection occurred from August through December 2006.

Study participants

The questionnaire was administered to households in rural Cambodia, where there were children reflecting the main types of disabilities described in the 2004 Cambodian Socio-Economic Survey (CSES) including: vision, hearing, mobility, feeling [tactile], and mental function (15). Thus, a purposeful approach to sampling was used, targeting households where

there was known to be a child with a disability, and using databases from several organisations that worked with people with disabilities in Cambodia. In some cases village leaders were asked to help identify households where there was a child with the type of impairment being looked for.

To choose the sample, first all children (0-18 years old) were selected in the databases, and the database were sorted by child's birth year into three groups that corresponded grossly to preschool age children, primary school-aged children, and those who might be in the workforce or secondary school. Next, these three age subgroups were sorted by type of impairment/disability to end up with subgroups stratified by age and type of disability. Finally, names were randomly chosen from each age-disability type subgroup until there was a total sample of 500, representing a range of ages and types of disabilities in Siem Reap and Takeo.

Study procedures

The six interviewers hired to complete all of the interviews received two and a half days of training and a detailed training manual to use as a reference. All materials were initially written in English and then translated into Khmer. During the training, the interviewers practised administering the questionnaires until they could administer the survey correctly on their own. Once in the field, interviewers were again supervised until the authors were assured of their consistency and competence. A field supervisor accompanied the interviewers on a daily basis in the field. She was responsible for quality control and logistics. She observed interviewers on a regular basis to ensure that interviews were handled professionally and according to protocol.

Interviewers were instructed to read an informed consent form aloud to all potential respondents, answer questions about the study, and make it clear that participation was optional. Interviews were conducted only if the informed consent form was signed with a thumbprint or signature.

Data analysis

The database "Access" was used to enter field data. Data were analysed descriptively using the SPSS statistical package. Initially, the data from the two provinces were analysed separately to determine whether there were differences between them. Only minor differences

were found in a few questions, so the decision was made to aggregate the data and analyse it as one dataset.

RESULTS

Household demographics

The majority of households surveyed, had 4-9 family members living at home with an average of 6.7 and range of 2-15. Almost half of the respondents (49% of households) were very poor, and reported making less than 1 US dollar per day. Another 33% reported making the equivalent of 1-2 US dollars, and only 18% made more than that.

Most of the respondents (71% of fathers and 74% of mothers) identified themselves as farmers. Other respondents stated that they were self employed, or labored for others. Ten percent of the fathers (48) and 5% of the mothers (18) were reported to be dead. The respondents in the two provinces differed somewhat, in years of education. In Siem Reap, the majority of caregivers of children with disabilities reported never having gone to school. In Takeo, there was more variation with a range of 0-12 years of education.

Over half of the children in the study (55%) were male, and 45% were female. In terms of age distribution, 20 (4%) were 1 year or younger, 78 (16%) were 2-5 years old, 271 (54%) were 6-14 years old, and 131 (26%) were 15-18.

History of health difficulty

Respondents could give more than one answer concerning the illness or injury that led to their child becoming disabled. A large percentage of respondents (40%) reported that their child had something wrong at birth (congenital condition), and that they were unaware of any services to help their infant. Sickness was identified as a causal factor in the child's disability for 46% of households. More than half of those who reported sickness as a major problem stated that the disease involved fever, often accompanied by convulsions. The next most commonly reported cause of disability was accidents (15%), followed by karma (10%) – a belief that the problem had to do with ancestors and/or a previous life. A large percentage of respondents (70%) indicated that the child's problem had started within the first year.

Families used a variety of services when their child developed a health condition, including traditional healers, hospitals, health centres, private facilities and providers, pharmacies, rehabilitation centres and village health volunteers. Generally, reported “helpfulness” was highest for hospitals and rehabilitation centres, but there was a range of satisfaction with each type of service used. A large proportion (67%) of respondents stated that they wished they had used additional services for their children, especially hospitals. The main barriers to service use included the costs of transportation, health services, and medications; costs associated with missing work or buying food; lack of knowledge about relevant services or how to access them; and distance to facilities. In summarising, parents suggested that the reasons their children eventually developed permanent disabilities were attributable to financial costs, poor or inadequate treatment, bad karma, bad luck and/or a lack of knowledge about the health care system.

Children’s impairments and functional difficulties

Respondents were asked about problems experienced by their children pertaining to seeing; hearing; communicating and interacting; learning, concentrating and remembering; holding and using objects; moving; emotional conditions (e.g. anxiety or depression); pain; breathing difficulties; and convulsions or blackouts. Some of these questions emphasised concerns associated with physical or mental impairments, and some pertained more specifically to activity difficulties.

The 125 respondents who reported that their child had “some difficulty” or “difficulty” seeing, were then asked about the use of eyeglasses. Eight or 2% of the group did wear glasses. The other 117 did not. Of this group who did not wear glasses, 29 respondents felt that the condition was not serious enough to warrant their use. Some stated that the condition was too serious to be amenable to glasses. Others identified barriers related to accessing and affording glasses or other equipment.

Of the 123 children who had at least some difficulty hearing, 5 wore hearing aids. Nineteen respondents felt that the condition was not serious enough for hearing aids, and the others did not know how to access or pay for them, felt that the condition was too serious for adaptive aids, or stated that the child was too young to wear them.

Table 1. Respondent report of child difficulty with body functions and activities

Does your child have difficulty with the following function or activity?	No	Sometimes	Yes	N/A*	Total 100%
Sensory performance					
Seeing	375 (75%)	49 (10%)	76 (15%)	0	500
Hearing	377 (75%)	41 (8%)	82 (17%)	0	500
Communication/relationships					
Speaking (child over 2 years)	295 (59%)	45 (9%)	142 (28%)	18 (4%)	500
Understanding when others are speaking	317 (63%)	86 (17%)	77 (15%)	20 (4%)	500
Playing with or talking to others	258 (52%)	104 (21%)	121 (24%)	17 (3%)	500
Cognitive/mental performance					
Learning at school or home	230 (46%)	121 (24%)	129 (26%)	20 (4%)	500
Remembering things	295 (59%)	109 (22%)	77 (15%)	19 (4%)	500
Concentrating on tasks	263 (53%)	78 (16%)	147 (29%)	12 (2%)	500
Sensory motor performance					
Gripping, holding, or using tools/ objects	352 (71%)	72 (14%)	70 (14%)	6 (1%)	500
Feeling things with the hands or feet	348 (70%)	70 (14%)	72 (14%)	10 (2%)	500
Movement-related performance					
Moving around in the house	329 (66%)	66 (13%)	94 (19%)	11 (2%)	500
Moving outside the house	301 (60%)	68 (14%)	118 (24%)	13 (3%)	500
Walking on an even surface (50 meters)	319 (64%)	53 (11%)	115 (23%)	13 (3%)	500
Climbing steps	310 (62%)	63 (13%)	114 (23%)	13 (3%)	500
Other factors associated with activity					
Emotional condition**	219 (44%)	143 (28%)	124 (25%)	14 (3%)	500
Pain	277 (58%)	130 (27%)	88 (15%)	5 (0%)	500
Breathing difficulty	344 (79%)	97 (19%)	59 (12%)	0	500
Convulsions or blackouts	342 (69%)	+	158 (32%)	0	500

*N/A applies to children that respondents felt were too young to demonstrate these skills.

**includes anxiety, sadness, worry, depression, and strange thoughts or ideas.

+ This question asked whether the child ever had “convulsions or blackouts – yes or no.”

A total of 208 children had some type of difficulty moving around (in the movement-related performance categories). Parents of 52% of those children reported the use of some type of mobility aid. That meant that 100 (or 48%) of the children with mobility concerns did not use any type of adaptive equipment or device. When asked why not, about 49 reported that they did not feel that the condition was serious enough. The other 51 indicated that they did not know where to find equipment or they were concerned that they could not pay for it.

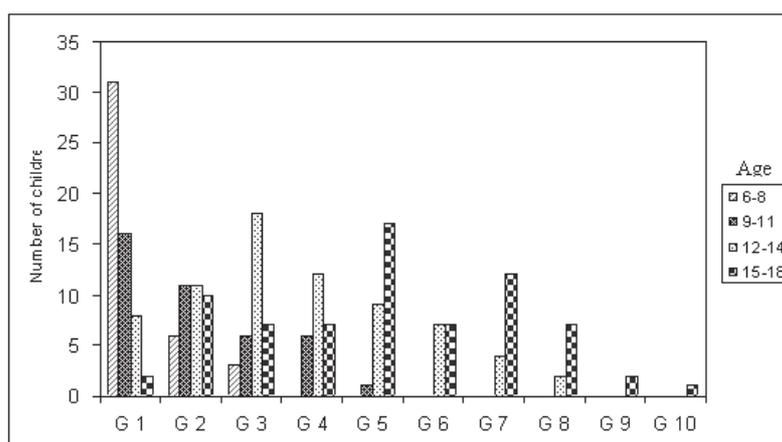
The number of functional difficulties listed by respondents (Table 1) ranged from 0-18. The mean number of difficulties was 7, and the most common answer was 3 (reported for 57 children), 4 (reported for 48 children), and 5 (reported for 56 children). Nine children had a health condition (e.g. a cardiac malformation) that had been treated, and did not currently interfere with activity.

Children's attendance at school

Ninety-eight children were less than 6 years old, and so would not be expected to attend school. This left 402 children who were school-aged. Of this group, 223 of them (55%) actually attended school, and of this group, 17 respondents reported that their children attended special education classes for the deaf or blind, provided by an NGO. The other 179 children (45%) did not attend school at all.

Many of the children who did attend school stopped after the early grades, so also the older children (Figure 1).

Figure 1: Grade Attendance and Age of Child



Children who did not attend school at all were reported to have difficulties in the whole range of functional categories (Table 2). No obvious patterns emerged.

Table 2. Function or Activity Difficulty and School Grade Completion

Activity that is difficult for child	No school	Grade 1	Grade 2	Grade 3 to 10	Total*
Seeing	30 (48%)	9 (14%)	5 (8%)	19 (30%)	63 (100%)
Hearing	31 (42%)	10 (14%)	9 (12%)	23 (32%)	73 (100%)
Speaking	82 (68%)	14 (12%)	10 (8%)	15 (12%)	121 (100%)
Understanding when others are speaking	41 (60%)	7 (10%)	6 (9%)	14 (21%)	68 (100%)
Playing with or talking to other	74 (72%)	9 (9%)	7 (7%)	13 (13%)	103 (100%)
Learning at school or home	74 (63%)	14 (12%)	9 (8%)	20 (17%)	117 (100%)
Remembering things	55 (80%)	5 (7%)	1 (1%)	8 (12%)	69 (100%)
Concentrating on tasks	70 (34%)	31 (15%)	24 (12%)	83 (40%)	208 (100%)
Gripping, holding or using tools, or other things	41 (69%)	5 (8%)	4 (7%)	9 (15%)	59 (100%)
Feeling things with his/her hands or feet	43 (68%)	6 (10%)	2 (3%)	12 (19%)	63 (100%)
Moving around in the house	53 (70%)	6 (8%)	3 (4%)	14 (18%)	76 (100%)
Moving outside the house	60 (65%)	9 (10%)	5 (5%)	19 (20%)	93 (100%)
Walking on an even surface for 50 meters	60 (65%)	8 (9%)	4 (4%)	20 (22%)	92 (100%)
Climbing steps	61 (69%)	8 (9%)	5 (6%)	15 (17%)	89 (100%)
Emotional condition	62 (53%)	14 (12%)	9 (8%)	31 (27%)	116 (100%)
Pain	37 (49%)	11 (15%)	5 (7%)	22 (29%)	75 (100%)
Breathing difficulty	29 (60%)	4 (8%)	1 (2%)	14 (29%)	48 (100%)
Convulsions or blackouts	68 (55%)	17 (14%)	7 (6%)	31 (25%)	123 (100%)

* Totals are for school aged children only, children under 6 were not included in this analysis

Reasons given for not attending school included: problems with transportation, teachers not knowing how to teach children with disabilities, difficulties with accessibility, lack of special equipment, expenses associated with school, sickness, pain, a need for the child to help with work around the house, and discrimination.

DISCUSSION

This household survey helped to clarify the functional picture of children with disabilities in rural Cambodia. It also assisted to identify important issues that must be addressed to meet the needs of children with congenital conditions or disabilities associated with injury and/or illness so that they are able to participate more fully in daily life activities.

Household considerations

When introducing the survey, interviewers asked to speak to an adult who had significant contact and caregiver responsibilities with the child with a disability, and in most cases, mothers responded. This is a reminder that at least certain aspects of any rehabilitation or disability prevention project, must target the mothers of children with disabilities, as they are the ones most actively involved in their child's care. In fact, it has been noted generally, that improving the educational and financial situation for women, often has positive consequences for families and societies at large (16).

Many of the parents in the households with a child with a disability, had a very limited educational background or no education at all. In comparison, half of the Cambodian population has had some primary school education (2). In addition, study respondents were poor, with 49% reporting making less than the equivalent of 1 US dollar per day as compared to 34% of the general Cambodian population (17). This data indicates that the study sample was over-representative of the very poor. In fact, it is apparent that the families in the study were unusually limited (even by Cambodian standards) in terms of education and resources. These associations do not necessarily indicate causal relationships, but certainly highlight a potentially pernicious cycle in which limited education, impoverishment, and poor health outcomes (in this case disability in children) may reinforce each other in an adverse manner.

Functional status of children

Children with a variety of "types" of disabilities were intentionally targeted. The study found a very high number of children with reported difficulties in all aspects of function including seeing, hearing, communicating, developing and sustaining relationships, cognitive aspects performance, sensory dimensions of task performance, and movement-related performance of activity. In addition, a surprisingly large proportion of children reportedly also had difficulty

with emotional problems, pain, breathing difficulty, and convulsions or loss of consciousness. Some children had distinct problems in one of these areas such as vision or hearing, and others had difficulties in multiple areas. Attempts were made to investigate whether there were associations between particular areas of impairment or activity limitations and cause of disability (e.g. accident, disease, congenital problem etc.), but no obvious patterns or relationships were found. Instead, any causal factor could and sometimes did result in a wide variety of impairments, activity limitations and participation restrictions.

School attendance issues

In the sample, 55% of school-aged children with disabilities were attending school, and this is actually much higher than previous estimates of school attendance by children with disabilities in Asian countries (18,19). However, an 81% primary school completion rate is reported for Cambodia (17), so children with disabilities are under-represented in comparison to their peers, and this is also similar to findings in other developing countries (20). A wide range of reasons were given for non-attendance, and all are worrisome as primary school is crucial to opportunities later in life. School non-attendance was not limited to children with any particular types of impairments or activity limitations. Clearly, there needs to be increased attention to addressing barriers to school attendance for the many children with disabilities who are not being mainstreamed adequately. In addition, there are almost no special education services available for the sub-group of children with complex or serious disabilities, who may need them.

Inadequate use of existing resources

It was found that some of the impairments and associated activity limitations were being addressed by international and local NGOs as well as other international organisations. For example, one NGO in Cambodia specialises in services for deaf children, and it was found that some of the families knew that and were using their services. In other cases, families obviously learned about services eventually, and reported that they wished they had used them earlier (e.g special services for vision impairments).

Unfortunately, it is equally clear that some families still did not know about available services. For example, some children with mobility disorders did not have assistive devices to aid

movement, in spite of the fact that there were rehabilitation centres in both of the surveyed provinces that offered relevant equipment. In other cases, families appeared to know about potential services, but worried about the costs, and were unaware that some services and facilities were free.

Finally, it is a matter of concern that many respondents did not seek any type of services because their child had a congenital condition, and they assumed that there was nothing that could be done for the child. While it is true that some parents believed that their child had a disability because of karma associated with past lives, **none** of them stated that this was reason to neglect the child's current needs in this lifetime.

These examples speak of the need for assertive outreach. If there are services available, then one needs to make sure that people know about them, are clear about how to access them, and understand which services are free of charge. It is a shame for needed services to go begging because people lack awareness or knowledge about them.

Gaps in services and resources

On the other hand, there are currently very limited early interventions available in Cambodia for children with multiple impairments (e.g. cerebral palsy). The physical rehabilitation centers provide a narrow range of services, and are not prepared to treat young children with complex conditions. The CBR services offered by NGOs are quite restricted by staff numbers and training. And finally, there are almost no services available for children with pain, convulsions, cognitive, or mental health issues, and yet, it is clear from the study results that the needs are there.

Study limitations

This study was administered only in 500 households in two provinces in rural Cambodia. Thus caution must be used in generalising the results elsewhere. Also, certain targeted databases were used to find households where there were children with disabilities. This means that the sample may be biased in certain ways (almost all of the households had some type of contact with an NGO), and not reflective of the entire population of households where there is a child with a disability in Cambodia.

CONCLUSION

The recently passed United Nations Convention on the Rights of Persons with Disabilities (21) reminds countries of their obligation to include people with disabilities in all systems and services. In the case of children, this means promoting full participation in home life and school. But awareness of rights does not always translate into action. Practical steps that reduce barriers and encourage inclusion, are needed as well.

In Cambodia as in other countries, mothers and other family members are centrally involved in their children's lives, so attending to family perspectives, concerns and suggestions will be critical to the well-being of children. Participatory approaches to working with families will need to be emphasised again and again. There is now a developing body of literature indicating that empowerment approaches to service delivery lead to better health outcomes (22).

Better data collection in developing countries to identify and describe children with disabilities is important, if relevant services are to be provided. For example, schools will be in a better position to mainstream children with disabilities, if they are clear about which types of accommodations are actually needed for specific types of impairments and they also know how many children have those impairments. The most recent Cambodian Socio-Economic survey did collect some data about people with different types of disabilities, and in the future, even more attention should be paid to thoughtful survey definitions and questions.

Some needs of children are being addressed and some are not. Highlighting successful programmes, scaling them up or replicating them (as feasible), and identifying the gaps will be necessary to more effectively meet service needs. This study provides data to help with those efforts. In Cambodia, as in many countries (23), a mix of public and private services provided by a mix of government actors, local and international NGOs, other international organisations and private providers, will probably continue to be required for many years.

Barriers to service use must be addressed. Many families of children with disabilities are poor and often unable to pay for services or transportation, so strategies must be devised to address financial hurdles such as cash conditional transfers for healthcare services (24). Other barriers are more informational in nature (e.g. not knowing which services are available or relevant) and need to be tackled through better early detection, more assertive outreach, and improved communication and collaboration between providers.

As in many countries, one could say that the glass is partially empty or partially full for children with disabilities in Cambodia. Some needed services are available, many are not. Some children are going to school, many are not. In the end, one must increase the visibility of children with disabilities, and strengthen the voices of those calling for inclusion. This study is offered as one small step in that direction.

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(My) Dying is Fun: A Comedy of Disabled Misadventures

Author: Christopher Day

At the peak of his career as an eco-architect, international lecturer and author, Christopher Day developed Motor Neurone (Lou Gehrig's) Disease. Initially, the future seemed bleak, but as his illness progressed, his attitude changed. Increasingly many things went wrong, but this only brought hilarity – and with it, new perspectives - to life. He began to appreciate the gifts illness has brought.

(My) Dying is Fun is for anyone, or anyone who knows anyone, who might one day die. For caring or providing for a person with disability, it is essential reading.

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