

# Understanding, preventing and minimizing consequences of childhood disability in rural Cambodia

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# A view of Cambodia

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# Handicap International (HIB) Background in Cambodia

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- HIB has been a major actor in the rehabilitation sector in Cambodia for decades
- Over time, HIB staff members have seen an increase in younger clients with a variety of problems in the rehabilitation centers
- In addition, HIB staff have become more aware of the potential for prevention or minimization of some of the disabilities that clients develop

# Background: Disability in Cambodia

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- Prevalence rate = 4.7% of the country (CSES 2005 data)
- Half of those with disabilities are under 20 years old (because of young demographic make-up of population)
- Leading causes of disability have changed over the years (landmine accidents are no longer a major new cause)

# Risk for disability in children

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- Children in Cambodia are at particularly high risk for disability because of:
  - Lack of antenatal care or skilled delivery for pregnant women (especially in rural areas)
  - Poor treatment or lack of treatment for childhood illness (respiratory, diarrhea, fever etc.)
  - Low vaccination rates in rural areas
  - Poor nutrition in early childhood

# Rationale for Study

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- It was clear that early childhood problems *could and probably did* lead to disability too often
- However, we needed to know more about the functional status of the children, and how families viewed and were using the health system when their infant or child had a congenital problem, injury or illness
- This information would then allow us to develop an intelligent secondary prevention plan

# Study Methodology:

## Participants

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- 500 households where there was an identified child with a disability (used existing databases)
- 250 in Siem Reap and 250 in Takeo provinces
- Included all major types of disabilities used in CSES (vision, hearing, mobility, feeling, mental, multiple)
- An additional 500 neighboring households where there was not a disabled child were also surveyed

# A Study Participant



# Study Methods:

## Questionnaire Development

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- Considered existing instruments (WHO DAS II, UNESCAP, Washington Group, 10 Question Questionnaire)
- Requested input from Disabled Peoples Organizations, NGOs, international organizations and Ministry of Health
- Developed two questionnaires: 1 for households with disabled children, plus one for neighboring households
- Pilot tested questionnaire in Phnom Penh and again in rural province

# Study Methods:

## Disability Questionnaire

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- Demographic information about the households
- Information about child's functional status (vision, hearing, speaking, understanding, playing, concentrating and learning, using hands, mobility, school participation, emotional status, pain)
- History of child's development of disability, and family's use/perceptions of health system
- Additional information about mother's pregnancy
- Environmental conditions at home

# Study Methods:

## General Household Questionnaire

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- Demographic information about households
- Perceptions about why people become sick and/or disabled in rural communities
- Perceptions about strengths and weaknesses of health system
- Beliefs about best treatments for different conditions
- Beliefs about people with disabilities

# Study Methods in the Field

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- Interviewer training and preparation
- Sampling frame (age and type of disability) and schedule
- Field supervision
- Informed consent
- Challenges of interviewing in a rural, developing country setting

# Interview Challenges

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# Interviewer at work



# Interviewer at work



# Interviewer at work

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# Study Results:

## Disability Questionnaire Demographics

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- 71% of respondents were mothers of the children and 13% were fathers
- Age range of children was 0-18, and 55% were boys
- Majority of respondents (72%) were rice farmers
- 47% of respondents had no education
- 48% of households lived on 1 US dollar per day or less (compared to 34% in general population)
- Typical household had 4-9 members at home
- Most homes lacked access to safe water or sanitation

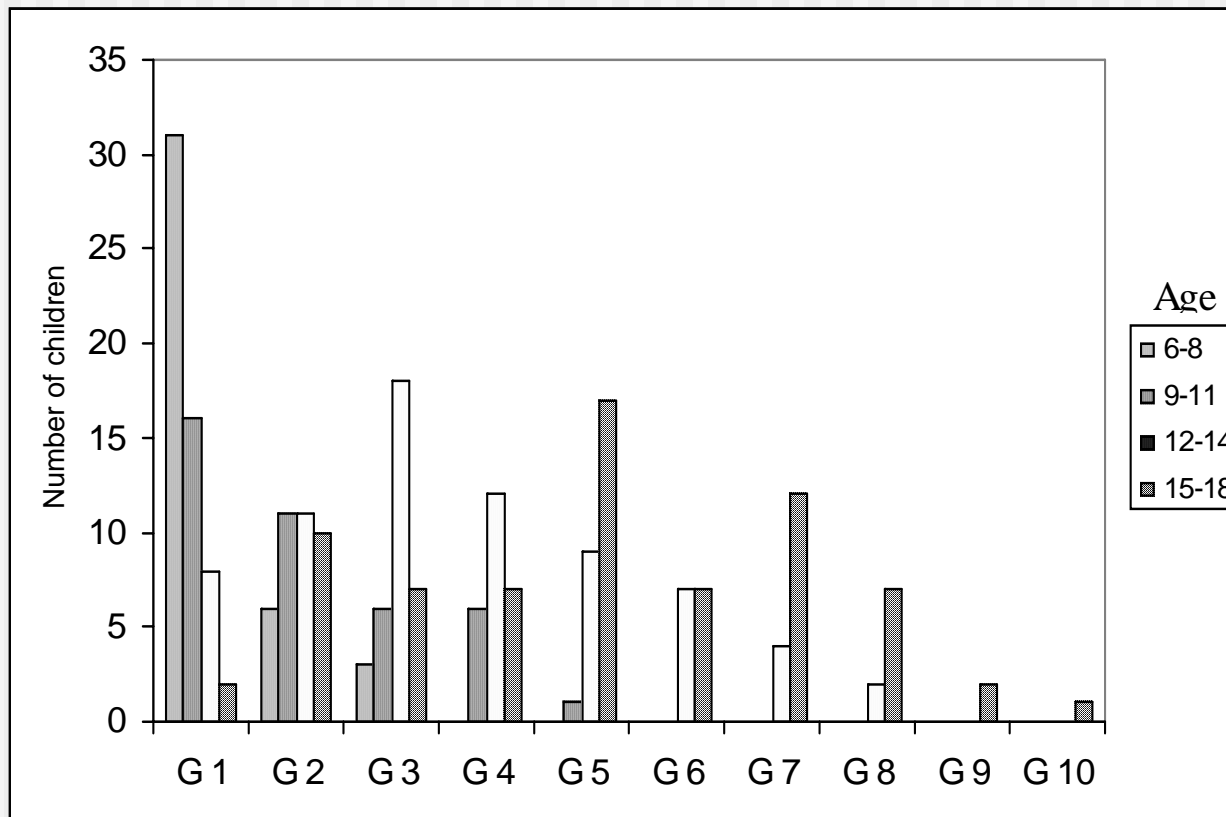
# Disability Study Results: Functional Status of Children

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- 125 of the 500 children had at least some difficulty seeing, but only 8 of them (2%) had eyeglasses
- 123 children had difficulty hearing, but only 5 had hearing aids
- 208 of the children had moving difficulties, but 100 of them did not have mobility devices
- Many children also had difficulties with speaking, learning, playing, sensory issues, emotional problems and/or pain
- 55% of school-aged children attended (some) school

# Grade Attendance and Age of Child

Figure 2: Grade Attendance and Age of Child



# Study Results:

## History of Disabling Conditions

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- 70% reported that problem began at birth or within first year (40% of this group reported a congenital problem)
- 46% reported sickness as causal factor (often high fever, sometimes with convulsions)
- Next most common cause was accident (15%), followed by karma (10%)
- Other identified causes included bad luck, injections, malnutrition, difficult birth, no vaccinations, violence, and chemicals or drugs

# Study Results:

## Use of Health Services

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- Households used a wide variety of services to help their child and reported varying levels of satisfaction with each one:
  - Hospitals (variety of types listed, private, public, specialty)
  - Traditional healers (highest use, but lowest satisfaction)
  - Health centers
  - Rehabilitation centers
  - Private providers and clinics
  - Pharmacies

# Study Results:

## Barriers to Use of Health Services

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- 67% of households wished they had used additional health services
- Barriers to health system use (real and perceived) included:
  - Cost of transportation (67%)
  - Cost of health care and medicine (40%)
  - Could not afford to buy food (27%)
  - Lack of knowledge (or trust) about health system (38%)
  - Distance to services (24%)

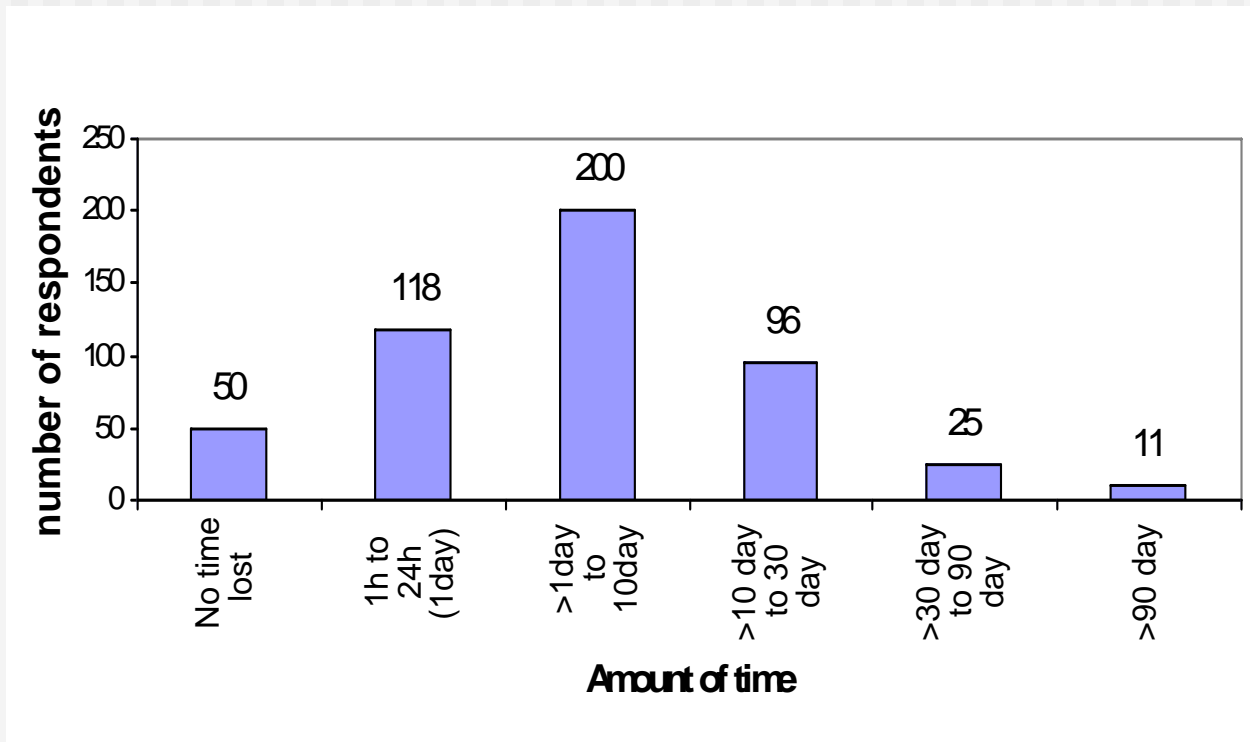
# Study Results: Transportation to Health Facilities

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Type of transport	Frequency (% of 500)
Motorbike	147 (29%)
Walked	83 (17%)
Taxi or tuk tuk	80 (16%)
Bicycle	60 (12%)
Other	28 (6%)
No transport needed	102 (20%)

# Study Results: Lost Parental Work Time

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# Study Results:

## Perceptions about Disability Development

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- Parents' summary of why their children developed a disability:
  - Lack of knowledge of health care system (37%)
  - Treatment costs (34%)
  - Medication costs (33%)
  - Poor or inadequate treatment (34%)
  - Bad karma (21%)
  - Bad luck (15%)

# Study Results: General Perceptions of the Health System (N=1000)

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- Respondents believed that the main causes of illness and injury in their communities included:
  - Poor sanitation (77%)
  - Poor nutrition (71%)
  - Poverty (65%)
  - Distance to health care (18%)

# Study Results: General Perceptions of the Health System

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- Respondents preferred traditional healer for broken bones
- For all other conditions respondents preferred the western health system
- Most would choose to take a family member to a hospital or health center for sickness or injury if they could
- However, the perceived cost barrier was viewed as prohibitive

# Study Results: Perceptions of People with Disabilities

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- 100% of respondents felt that people with disabilities deserved treatment to improve their quality of life
- Most also felt that people with disabilities should be allowed to:
  - Go to school (98%)
  - Work (97%)
  - Marry (88%)
  - Have families of their own (91%)

# Identified Issues from the Study

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- Many children with disabilities have congenital conditions or problems early in life
- Families do not seek treatment because of costs; or lack of awareness of risks or treatment options
- Parents of children with disabilities have limited resources (time and money)
- There are very limited services available for disabled children with mental/emotional problems or complex conditions

# Recommended Approach: Direct Action

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- There is a need for screening and early detection activities by local providers (traditional birth attendants and volunteers):
  - recognize serious illness or injury and refer families to hospitals and health centers
  - Recognize congenital or other developmental problems and refer families appropriately

# Recommended Approach: Direct Action

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- There is a need for community-based intervention services
  - Families of children with disabilities need low-cost, local, simple interventions and solutions to help their children function as effectively as possible at home and school
  - Families need help to overcome barriers to using currently available services and to keep children participating at home, school and in the community
  - Providers need to listen carefully to families in order to provide relevant and realistic services

# Recommended Approach: Inter-sectoral Partnerships

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- There is a need for organizations and entities involved in disability-associated work to communicate and collaborate well at all levels:
  - Private hospitals and clinics
  - Public Health System (Ministry of Health)
  - School system (Ministry of Education)
  - Rehabilitation Services (Ministry of Social Affairs)
  - Other local and international NGOs and organizations addressing maternal/child health, education, environmental conditions and economic development

# Reflections: Health, Poverty, and Disability

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- This study suggests that a poorly functioning primary health care system is associated with increased disability in the population
- The study also supports concerns that disability is associated with poverty

# Further Reflections

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- The term “disability” is too vague and broad to allow useful operational responses. To address real needs it will be necessary to talk about specific impairments associated with contextual facilitators. For example, when considering school attendance:
  - Mobility-challenged children need physical access and adaptive equipment
  - Blind and deaf children need special communication systems
  - Children with mental impairments need special assistance

# Final Reflections

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- Community-based rehabilitation has many strengths, but fails without adequate resources and support
- Families do the best that they can. We need to pay attention and build on the what they are already doing