



**Increasing inclusion of  
persons with disabilities:  
Reflections from disability  
research using the ICF in  
Afghanistan and Cambodia**

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## **Leonard Cheshire Disability and Inclusive Development Centre**

### **Increasing inclusion of persons with disabilities: reflections from disability research using the ICF in Afghanistan and Cambodia**

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## **ABSTRACT**

Purpose: Useful data that go beyond basic disability prevalence are needed to provide guidance to those who seek to dismantle barriers to full participation in daily life. This is especially true in the developing world where many people with disabilities are at risk of exclusion from involvement in community and societal activities and roles. This paper discusses participation of children to school based on disability surveys completed in Afghanistan and Cambodia.

Method: Both studies used the World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF) as a conceptual framework for survey design and questionnaire development, and both were intended to provide useful information to assist program and policy development.

Results: Some of the findings from the studies are compared and contrasted for these two developing countries at different stages of post-conflict development. 45% and 64% of children with disabilities respectively in Cambodia and Afghanistan were not attending school. The majority of children with disabilities who did attend school stopped after the early grades.

Conclusions: ICF is potentially a strong framework for disability research that can assist international development efforts. We note that cultural differences will always impact results, and challenge the extent to which it is possible to do comparative disability research.

### **Keywords:**

ICF, international development, disabilities, educational inclusion, cultural perceptions

## **Introduction**

Researchers, policy makers, and persons with disabilities all agree that there is a need for a scientific basis and valid conceptual framework in establishing disability statistics [1]. However, measurement and analysis issues regarding persons with disabilities remain particularly complex. Various models, theories and definitions propose different perceptions of the phenomenon, ranging from the extremely medical to the very social; and it is understood that cultural context is also relevant to understanding disability [2-3]. This has the effect of making it hard to compare different disability studies, because they are likely to use different definitions, concepts, terminologies, and measurement tools. Even studies focusing on basic prevalence of disability in different countries have established very different rates, probably reflecting a variety of ways of measuring disability. In addition, quite a bit of the existing disability literature compares measures of prevalence in developed countries [4-6]. To date, limited research has been conducted comparing methods or results of disability studies for different low-income countries focusing on accessibility [7].

The World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF) has been used in recent years to improve and standardize the measurement of disability [8]. The ICF attempts to incorporate aspects of many models, and takes into consideration the health condition, the individual situation, the collective resources, and limitations that may turn an individual impairment into a social disability. The increasing acceptance of the ICF is an important step in facilitating disability research that can be used to provide valuable information to governments, policy makers, international organizations, and persons with disabilities in advocating for inclusive, barrier-free societies and communities.

This paper describes disability survey research completed independently in Afghanistan and Cambodia. Both studies used the ICF as a framework for

instrument development. The purpose of the research studies, research design and instrument development will be described for both surveys. In addition, a few results from each study focusing on school attendance and participation of children with disabilities will be presented in order to facilitate discussion of disability research and methodological issues. Implications for researchers and policy makers will be explored.

### **Conceptual framework: the ICF**

The ICF is a recent innovation of the World Health Organization, which attempts to chart a middle path between medical and social models of disability, suggesting that both have validity. In the ICF, individuals are characterized as being disabled if they have impairments, if they experience activity limitations, and/or if they experience restrictions in community participation. The ICF identifies a number of interactive component parts that have an impact on the development of disability. These components include [9]:

*Health conditions* – diseases and disorders that may be associated with development of disability

*Body functions and structures* – these may be physiological or psychological in nature, and are characterized as mental; sensory and pain; voice and speech; cardiovascular; immune and respiratory; digestive; metabolic and endocrine; genitourinary and reproductive; neuromuscular and movement-related; and skin and related structures. Problems in body functions are referred to as *impairments*.

*Activity* – refers to task execution, and difficulties are called *activity limitations*.

*Participation* – refers to involvement in life situations, and difficulties are called participation restrictions.

*Contextual factors* – emphasize the importance of non-impairment factors in the development of disability, and include *environmental factors* (such as products and technology; natural and built environment; support and relationships; attitudes; and services, systems and policies).

*Personal factors* are another aspect of context, and include individual characteristics such as age, gender and education.

Using the ICF in a population-based survey implies a complex approach to the measurement of disability. The ICF consists of a scale of reference: its domain codes require the use of qualifiers, which identify the presence and record the severity of the functioning problem on a five-point scale (e.g. no impairment, mild, moderate, severe, and complete). To take full advantage of the coding requires that a large amount of information be collected: information about activity or participation in sufficient detail to assign ICF domain codes; information about the use of personal assistance and assistive technology; and assessments of five levels of difficulty in both the current environment and within a standardized environment. None of the question sets currently used or recommended by international organizations covers the entire range of information needed to assess all the qualifiers of the ICF. In fact, the multi-dimensionality of disability in the ICF may lead to various ways of operationalising the concepts, and to a large range of types of questions, which can be used or created [10].

### **Study context and methods in each country**

#### *Afghanistan*

Afghanistan has been in turmoil since 1979. Among many other consequences of the conflict, there are a huge number of people disabled by war or as a result of bad health care, a lack of maternal and prenatal health care and preventable disease. About 600 children under five die every day in Afghanistan due to pneumonia, poor nutrition, diarrhoea and other preventable diseases [11]. Access to essential health services and basic commodities, sufficient food ratio, safe water or adequate sanitation, and also to education are key in reducing rates of maternal and child mortality and disability. The Human Development Index for Afghanistan in 2005 is presented as 0.312 which places it last on the list. [12].

The disability prevalence rate in Afghanistan is estimated at 2.7% of the population when considering very severe disability, but increases to 4.6% when various forms of mental distress are included [13]. Based on the former, a majority of persons with disabilities are in the 0 to 14 years age group, but, compared to the total age class, the proportion of persons with disabilities under 15 or even under 20 is lower than the same proportion in the age class above 45. Disability prevalence is higher in older people, yet disability from birth, or acquired during the first year of life, represents 26.4 % of the total identified causes [14]. Lack of maternal and antenatal care, a low level of vaccinations, inadequate healthcare, congenital disabilities, accidents or/and malnutrition and preventable diseases such as polio or tuberculosis explain many of the impairments from birth. A high rate of birth complications, especially in undernourished women with inadequate care, is also associated with disabling conditions such as cerebral palsy.

In Afghanistan, the international non-governmental organization Handicap International (HI) was funded by several donors (European Commission, UN agencies, Swiss and French cooperation) to carry out a national survey on disability, with measurements of: prevalence, livelihoods, access to services, activity, income, self perception, and social participation of persons with disabilities. The aim of the survey was to provide policy guidelines for the Government of Afghanistan in a country where state support structures still needed to be implemented in most parts of the country. The study was designed based on the Capability Framework [15], which focuses on the 'capability set that a person has, that is, the substantive freedoms he or she enjoys to lead the kind of life he or she has reason to value' (p. 87). Emphasis was placed on individual and societal factors influencing the lives of persons with disabilities, and institutional factors were addressed to a lesser extent. The study also employed the ICF as a framework for survey question development. The first research phase (6 months total) was used for participatory qualitative research. One member of the research team was a technical advisor within the Ministry of

Martyrs and Disabled [16], and he engaged in extensive interviews, focus groups, and meetings with stakeholders including disabled persons organisations, UN and donors agencies, NGOs, other ministries before developing a survey instrument.

The resultant National Disability Survey was a three-stage random sample probability proportional to size survey, based on the administrative organization of Afghanistan in 34 provinces, 397 districts and 32,000 villages. The sample size of 5,250 households was chosen for its power of estimation. The first stage of sampling was within the district; the second stage of sampling was to locate the village or section of town; and in the third stage of sampling, a constant number of 30 households per cluster were randomly selected. All the persons with disability older than 4 years old were interviewed. *For this paper, we consider only respondents between the ages of 4 and 18, unless otherwise specified.*

The detection of persons with disabilities was accomplished through a screening questionnaire comprised of 27 questions and different sections relating to physical and mental disabilities. The head of household answered the screening questions regarding all the members of his household. The questions were categorized as physical, sensorial, psychological, intellectual and relational, and were formulated based on the dimensions outlined in the ICF including body functions and structures, activities, and participation. In order to make questions neutral, the NDSA chose to use the term 'difficulty' or 'mushkel' in *Dari*, as this term is less threatening and constitutes less of a 'label' for the persons concerned than the word for disability.

### *Cambodia*

Cambodia has also experienced extensive social and economic turmoil in recent decades. It is reported that 500,000 tons of American bombs were dropped on Cambodia between 1972 and 1974. During the subsequent Khmer Rouge



regime, more than 1.5 million (out of 7 million) people died. This was followed by a turbulent period of occupation by the Vietnamese, and finally a period of civil strife, which lasted well into the 1990s (Chandler, 2000). All of these events severely weakened the basic infrastructure, educational and health systems, and the economy, which have only begun to stabilize and grow again in the last 10 years [17].

Cambodia ranks 131st out of 177 countries in the United Nations Human Development Index (HDI) and 85th of 108 developing countries for the Human Poverty Index [12]. There are now about 13 million people in the country, and because of a high birth rate, children make up almost half of the population [18]. Over 84% of Cambodians live in rural areas, and approximately 35% of the population lives below the poverty line [19].

The disability prevalence rate in Cambodia is estimated at 4.7% of the population [20], meaning that more than half a million people in Cambodia have a disability. More than half of those with disabilities are under 20 years of age. Factors placing children at high risk for disability include lack of antenatal care or skilled delivery assistance for pregnant women, serious childhood illnesses (e.g. acute respiratory conditions or chronic diarrhoea) that go untreated, low vaccination rates (especially in rural areas), and high rates of children whose growth is stunted or who are underweight [21].

In Cambodia, Handicap International Belgium (HIB) has been one of the main providers of rehabilitation since the mid 1980s. Initially most of their clients were adults who had experienced landmine accidents. But gradually, over time HIB noted that more people seeking rehabilitation services were young, and many seemed to have developmental conditions such as cerebral palsy. HIB wanted to provide relevant services to this clientele, and also to understand whether it might be possible to undertake secondary prevention programs to minimize or even prevent some of the disability they were encountering. Thus, they sought

and received funding from the Belgian Technical Cooperation (BTC) to fund a study designed to better understand the impairments and functional limitations of children with disabilities, and to clarify the events leading to resultant disability in these children [22]. Funding for the study was quite modest, which meant that the study was less extensive than the one carried out in Afghanistan.

The study targeted 500 households in two rural provinces where there was a child with a disability. The provinces chosen were ones where HIB had long-standing physical rehabilitation centres and strong relationships with local NGOs providing community-based rehabilitation services. A purposeful approach to sampling was used based on databases from several international and local organizations that worked with people with disabilities in Cambodia. In some cases village leaders were also asked to help identify appropriate households. The selected sample was stratified to include children of all ages (0-18 years old) and all types of disabilities as described in the 2004 Cambodian Socio-Economic Survey including: vision, hearing, mobility, feeling (tactile), and mental function [18].

As suggested earlier, the study used the ICF as a framework for viewing disability. The authors wanted to learn about the children's body function and structure impairments, activity limitations and participation restrictions. They also wanted to know the parents' perceptions of the cause of the disability, how they had used the healthcare system, and their perceptions of the effectiveness of services their children had received. Questionnaire development drew from the World Health Organization Disability Assessment Schedule or WHODAS II [23], the WHO/UNESCAP Disability Questionnaire Version A [24], the Washington Group Question Set [25], and The Ten Question Questionnaire [26]. Field testing in rural Cambodia suggested that none of these instruments would work without modification and revision, so in the end a survey tool was developed that built on all of them. As with the study in Afghanistan, the researchers steered clear of

asking respondents about having 'a disability', instead choosing to ask if they had 'difficulty' with various activities.

### **Study results: disability perceptions and school attendance**

This section does not present all of the results of the two surveys, which are reported elsewhere [22,27-30]. In addition, although both studies were guided by the ICF, they were developed separately (using different sampling frames, questions, interviewing systems etc.), so analysis for this paper does not use direct comparisons between the two countries. However, based on similar lines of questioning, we are able to explore perceptions of the cause of disabilities in each country as well as cultural attitudes toward people with disabilities in general. Basic attitudes and perceptions have an impact on all aspects of involvement in society, and are critical to understanding how to address barriers to access and participation. Next we examine educational participation of children with disabilities, as this topic was explored in both the Afghanistan and Cambodia studies. Integration of children with disabilities in school makes them more visible in the community, enhances participation and acceptance, and assures better opportunities for employment and social engagement in adulthood [31], and is one of the Millennium Development Goals [32]. Examining school attendance and completion results from each country also allows for consideration of measurement issues, and facilitates comparisons of similarities and differences between countries.

#### *Afghanistan*

People in the study were asked what caused their disability. In some cases the answer was clearly associated with a traumatic incident (e.g. an explosion or violence), but in other cases explanatory reasons were less concrete, for example: "it is my destiny" or "it is a curse of God, Djins or a result of black magic".

**Table 1: Perceptions about why child in Afghanistan developed a disability**

Reason Given	N=347	%
From birth or during the first year (genetic illness ...)	177	51.0
Landmine or unexploded ordnance	10	2.9
Other war injury (bullet, grenade, bomb, booby trap)	11	3.2
Work accident	1	0.3
Home accident	27	7.8
Road accident	6	1.7
Disease	51	14.7
It is my destiny, a curse or black magic	44	12.7
After a tragic personal event	7	2.0
Other or unknown cause	13	3.7

Source: NDSA

Recent efforts to increase the number of schools and teachers in Afghanistan in order to facilitate accessibility have been jeopardized by the increase in attacks against schools, especially in the Southern part of the country. In Table 2, we consider access to some form of schooling, even if children went to school for a very limited period before dropping out.

**Table 2: School Attendance in Afghanistan**

Age and Gender	Non disabled N=961 (%)	Children with Disabilities N= 302 (%)
7 to 14 years old	504 (65.4** <sup>(1)</sup> )	86 (36.1** <sup>(1)</sup> )
15 to 18 years old	56 (37.3)	22 (32.8)
Male 7 to 18 years old	388 (68.3**)	80 (48.5**)
Female 7 to 18 years old	172 (43.2**)	25 (15.2**)
All 7 to 18 years old	560 (59.4** <sup>(2)</sup> )	105 (35.4** <sup>(2)</sup> )

Source: NDSA. Note: (1) Test of comparison of proportion between disabled and non disabled people. \*\* Significant at  $p < 0.01$  \* Significant at  $p < 0.05$ . (2) Test Chi 2 of Pearson of independence. \*\* Significant at  $p < 0.01$  \* Significant at  $p < 0.05$ .

Access to education is higher for the new generation of children at school age, but is (as it also was for former cohorts) significantly different for children with and without disabilities. The proportion of non-disabled children aged 7 to 14 accessing public school today is almost twice as high as the proportion of children with disabilities disabled before school going age regardless of where they live, their gender or their generation. The gap in attendance between disabled and non-disabled children was lower for children between 15 and 18 years old. This may be due to the fact that war was going on when those children were of school age and many of them, regardless of disability, did not have

access to school. Table 2 also shows the large difference in access between girls and boys.

Table 3 provides a more detailed examination of school exclusion, completion of primary education and literacy rates by body function and activity limitation type. The highest level of exclusion from school was observed for children experiencing epilepsy, and similar levels of exclusion were observed for children with sensory types of body function limitations learning difficulties, or emotional problems. The lowest levels of exclusion were observed for children with mobility limitations. The level of drop out before the end of the primary cycle of education is very high. The lowest rates of completion of primary school are observed for children with fits or epilepsy sensory difficulties, and some behavioural difficulty. Literacy rate are also very low. Generally, children who have a mobility difficulty do better at the primary and secondary level than children with other types of functional difficulties.

**Table 3: Body Function or Activity Difficulty and School Exclusion, Primary Education Completion and Literacy Rate in Afghanistan**

<b>Body function or activity</b>	<b>No School (%)★</b>	<b>Finished primary (%)T</b>	<b>Secondary school (%)T</b>	<b>Literacy rate (%)T</b>
Experienced fits/epilepsy	59 (78.7)	2 (4.1)	2 (4.1)	9 (18.4)
Learning new things easily†	19 (76.0)	3 (12.0)	2 (8.0)	4 (16.7)
Talking to others	101 (75.9)	2 (3.2)	2 (3.2)	6 (9.7)
Making yourself understood	90 (73.2)	4 (6.9)	3 (5.2)	5 (8.6)
Feeling Sad, Crying for no particular reason	91 (72.2)	6 (8.1)	3 (4.1)	13 (17.6)
Hearing	45 (71.4)	2 (5.4)	0 (0.0)	6 (16.2)
Finding the way to express what you need	90 (70.9)	7 (11.5)	6 (9.8)	11 (18.0)
Experienced violent behaviour regarding yourself	41 (70.7)	4 (11.1)	3 (8.3)	5 (13.9)
Understanding when others are speaking	74 (70.5)	4 (8.0)	1 (2.0)	5 (10.0)
Going to the toilet	60 (70.0)	7 (14.6)	4 (8.3)	15 (31.3)
Fainting or passing out	65 (69.9)	4 (7.4)	3 (5.6)	10 (18.5)
Concentrating on tasks†	13 (68.4)	5 (26.3)	4 (21.1)	5 (26.3)
Experienced verbally violent behaviour towards another person without any reason	50 (67.6)	5 (12.2)	3 (7.3)	8 (19.5)
Moving outside the house/go to the bazaar	155 (66.8)	13 (10.7)	8 (6.6)	35 (28.7)
Remembering things	110 (66.7)	9 (11.0)	6 (7.3)	14 (17.1)
Getting dressed	74 (66.1)	8 (13.3)	5 (8.3)	17 (28.3)
Eating/drinking	27 (65.9)	3 (13.0)	2 (8.7)	7 (30.4)
Feeling comfortable with people	75 (65.8)	4 (7.7)	3 (5.8)	9 (17.3)
Keeping calm, staying in one place	54 (63.5)	3 (8.3)	1 (2.8)	7 (19.4)
Climbing steps	91 (62.7)	16 (19.0)	9 (10.7)	32 (38.1)
Experienced physically violent behaviour towards another person without any reason	32 (62.7)	7 (20.6)	5 (14.7)	9 (26.5)
Carrying heavy things	130 (62.5)	18 (15.9)	12 (10.6)	37 (32.7)
Going out of the house because you feel scared	63 (62.4)	4 (7.7)	4 (7.7)	13 (25.0)
Having repetitive, stereotyped body movements	39 (61.9)	4 (10.8)	3 (8.1)	11 (29.7)
Bathing of ablution (before praying)	100 (60.6)	11 (15.1)	8 (11.0)	22 (30.1)
Going out of the house because people look	44 (58.7)	6 (13.6)	6 (13.6)	12 (27.3)
Seeing	19 (55.9)	4 (17.4)	3 (13.0)	7 (30.4)
Preparing meals for yourself	151 (55.1)	12 (11.8)	3 (4.5)	31 (30.4)
Moving around in the house	115 (53.7)	13 (16.7)	8 (10.3)	27 (34.6)
Riding a bicycle or an animal	274 (53.3)	21 (8.9)	14 (5.9)	80 (33.8)
Working in the field	286 (51.6)	24 (10.2)	13 (5.5)	83 (35.2)

Source: NDSA. Note: ★ Totals are for school-aged children only; children under 6 were not included in this analysis. T For children aged 12 to 18. † Only for children aged 15-18 years old.

Table 4 explores reasons for non-attendance at school. Results indicate that exclusion from education is slightly higher when the child becomes disabled before school age than when the age of disability onset is older. This may be explained by the considerable primary school enrolment effort that has been made by the Government since 2002. This effort has been seen to mainly benefit

non-disabled boys, but there is evidence to show that, to some extent girls and disabled children have benefited too.

**Table 4: Main Reasons Given for School Non-Attendance by Age and Gender in Afghanistan**

Age Groups	Main Reasons for having received No Education	Persons Disabled before age 7			Persons Disabled after age 7 and Non-Disabled		
		Male (%)	Female (%)	All (%)	Male (%)	Female (%)	All (%)
Age 7 to 14	Absence of School	18 (30.6)	11 (15.3)	22.4	56 (47.9)	64 (34.8)	39.1
	Disability	36 (58.1)	36 (50)	53.7	1 (0.9)	1 (0.5)	-
	School not for girls	NA	12 (16.7)	-	NA	75 (41.8)	-
Age 15 to 25	Absence of School	3 (8.8)	6 (25)	15.5	48 (40.2)	105 (44.1)	42.7
	Disability	15 (44.1)	12 (50)	46.6	5 (3.9)	1 (0.5)	-
	School not for girls	NA	4 (16.7)	-	NA	66 (33.7)	-
age >26	Absence of School	16 (37.2)	12 (50)	41.8	197 (45.8)	193 (59.7)	57.7
	Disability	19 (44.2)	2 (8.3)	31.3	8 (2.2)	2 (0.6)	-
	School not for girls	NA	8 (33.3)	-	NA	88 (30.3)	-

Source: NDSA.

As illustrated by Table 4 respondents reported that “having a disability” was an important reason for non-attendance at school for all age groups, especially those who were younger. However, persons over the age of 25 stated that the main reason for having received no education was the absence of schools in their communities. In fact, for men and boys who were disabled after age 7 and the non-disabled, absence of a school was the reason most commonly given by all generations. For girls and women, gender was the third major reason for not going to school. Heads of households often stated that school was unnecessary for girls. Other reasons not specified in the table given by the respondents for not sending children to school were absence of financial means, need for the child to work, bad political situation and useless schools.

## *Cambodia*

The researchers in Cambodia were interested in learning parental attributions concerning why their child developed a disability, as this is an important aspect of social perceptions and beliefs about disability. Respondents could give more than one answer, and answers ranged from very practical considerations to those that were more religious or cultural in nature.

**Table 5: Perceptions about why Cambodian child developed a disability**

<b>Reason Given</b>	<b>N*</b>	<b>% (N= 500)</b>
Lack of knowledge about health system	185	37
Cost of treatment	176	35
Poor or inadequate treatment	170	34
Lack of money for medicine	163	33
Bad karma	106	21
Bad luck	74	15
Lack of money for transportation	25	5
Child just born that way	22	4
Bad advice from others	7	1
Other**	60	12

Source: Cambodia study \* Numbers equal more than 500 because respondents could give multiple answers  
\*\*Other responses included malnutrition, lack of time to get care, too far from services, didn't seek treatment for child

The researchers were also interested in learning about Cambodian perceptions of people with disabilities. A general set of survey questions was administered in the 500 households where there was a child with a disability and also in 500 neighbouring households as well. One component of the survey asked a number of questions designed to assess respondents' perceptions of people with disabilities. All 1,000 respondents felt that people with disabilities deserved treatment to improve their quality of life. Similarly, 98% thought that children with disabilities should be allowed to go to school, and 97% felt that adults should be able and allowed to work. Somewhat fewer respondents, (88%) believed that people with disabilities should be allowed to get married, and 91% thought that it was appropriate for them to have children. Those who felt that people with disabilities should not get married or have children often pointed to practical concerns that it would be hard for them to work, make a living, and feed a family. Some suggested that it would be difficult for a person with a disability to attract a spouse, and that discrimination or poor treatment by others might make daily



activities and tasks problematic or put the person at risk for harm. Interestingly, no one mentioned karma as a rationale for differential treatment although they sometimes felt that karma explained why people developed disabilities.

Cambodia has slowly been rebuilding its educational system after decades of conflict and isolation. By 2006, the net enrolment rate was reported at 91% (90% for girls) at the primary school level, 31% (30% for girls) at the lower secondary level, and 11% (10% for girls) at the upper secondary level [33]. The World Bank reported a somewhat lower 81% primary school completion rate in Cambodia for 2005 [17].

As the Cambodian study targeted households with children with disabilities, the authors could not do a direct comparison of school attendance rates for children with and without disabilities in the targeted provinces. However, the study did examine school attendance of children in the survey sample. Of the children in the study, 98 were less than 6 years old, and would not be expected to attend school. This left 402 children who were school-aged. Of this group, 223 (or 55%) actually did attend school, and 179 (or 45%) did not attend at all. The majority of children with disabilities who did attend school stopped after the early grades. These numbers are obviously quite low in comparison to the national enrolment rates. Parents in the study reported removing their children from school for a wide range of reasons including: difficulty with transportation, unsupportive teachers, problems with physical access, lack of required adaptive equipment, expenses associated with school, sickness and/or pain, and general discrimination against the children. Some parents reported multiple reasons.

Children who did not attend school (or attended on a limited basis) were reported to have difficulties in the whole range of functional categories as described in table 6. The level of drop out before achieving the primary cycle of education was globally very high. Access to secondary school was extremely limited,

ranging from 2.5% of those with speech impairments to 14.6% for those reported to have difficulty remembering things.

**Table 6: Body function or activity difficulty and school grade completion in Cambodia**

Activity that is difficult for Cambodian child	No School (%) *	Finished Primary school * (%)	Lower secondary school (%) #
Seeing	41 (43.2)	12 (18.0)	6 (9.0)
Hearing	31 (34.8)	10 (17.0)	8 (12.7)
Speaking	83 (61.9)	3 (4.0)	2 (2.5)
Understanding when others are speaking	67 (58.3)	7 (9.8)	5 (6.7)
Playing with or talking to others	96 (57.1)	11 (10.1)	6 (5.2)
Learning at school or home	97 (49.5)	20 (15.5)	12 (8.8)
Remembering things	82 (56.9)	56 (38.9)	6 (7.1)
Concentrating on tasks	82 (32.9)	9 (11.0)	24 (14.6)
Gripping, holding or using tools	55 (56.1)	38 (24.5)	5 (8.6)
Feeling things with hands/feet	62 (57.9)	8 (15.3)	6 (8.6)
Moving around in the house	58 (52.7)	9 (13.5)	6 (8.6)
Moving outside the house	62 (47.7)	15 (19.8)	10 (12.7)
Walking on an even surface 50 m	57 (49.1)	10 (14.4)	7 (9.7)
Climbing steps	63 (50.4)	12 (16.7)	9 (12.0)
Emotional condition	105 (47.7)	24 (16.4)	17 (11.1)
Pain	68 (39.8)	24 (22.2)	15 (13.0)
Breathing difficulty	52 (47.3)	11 (14.7)	8 (10.4)
Convulsions or blackouts	89 (35.7)	36 (22.7)	23 (13.9)

Source: Cambodia survey. Note: \* Totals are for school-aged children only; children under 6 were not included in this analysis. \* For children aged 12 to 18. # For children aged 12 to 18.

We also explored access to resources associated with specific impairments. In the sample, 125 out of the 500 children were reported to have “difficulty” or “some difficulty” seeing. However, only 8 of these children wore glasses and the other 117 did not. Parents reported that the condition was not serious enough to warrant glasses, or in some cases, too serious. Others identified barriers related to accessing or affording glasses. In addition, a series of questions were also asked to gauge how many of the children with disabilities had movement and mobility performance problems as seen in table 7.

**Table 7: Cambodian respondent report of child movement-related performance on tasks**

Does your child have difficulty with the following task?	No (%)	Sometimes (%)	Yes (%)	N/A* (%)	Total (100%)
Moving around in the house	329 (70)	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 500 m	319 (64)	53 (11)	115 (23)	13 (3)	500
Climbing steps	310 (62)	63 (13)	114 (23)	13 (3)	500

Source: Cambodia survey. \*N/A applies to children who respondents felt were too young to demonstrate these skills

Parents of 52% of the children with moving difficulties reported the use of some type of walking aid (wheelchair, prosthesis, orthotic device or crutch). That meant that 48% of them did not use any type of adaptive device. Some respondents reported that they didn't think the condition was serious enough. But many others indicated that they did not know where to find equipment or were concerned that they could not pay for it.

## Discussion

### *Methodological Considerations*

Both Afghanistan and Cambodia share some characteristics including a recent history dominated by conflict, and low performance in terms of development as shown by various indexes. This makes it interesting to do some disability study comparisons. However, the two studies were undertaken for different reasons, in different cultural and geographic contexts, and with different resources. The Afghanistan study was national in scope and included households with and without family members with disabilities. The Cambodian study was restricted to households where there was a child with a disability in two provinces. Methodologies adopted were defined according to study objectives, and also had to take cultural factors into account. These differences highlight an important limitation in our retrospective attempt to do a comparative study: different

instruments give different types of information that can only be analyzed comparatively with caution.

However, we argue that certain factors make possible some attempts at comparison. Firstly, both surveys were based on the ICF framework, allowing us to examine how health conditions, impairments, and context come together to facilitate and/or impede an individual's ability to engage in a variety of activities and participate in society [34]. And it is clear that both studies did ask similar types of questions (e.g. about body function impairments, activity limitations and participation restrictions). Secondly, similar findings indicate ongoing and multi-dimensional access barriers to education for children in both post-conflict countries. School participation and accessibility of services and resources for children with disabilities are a central topic in the UN Convention of the Rights of Persons with Disabilities as described in articles 24 and 25:17-18 [35], and it is clear that much more needs to be done to assure that children with disabilities actually receive an education in the developing world.

### *Disability perceptions*

The social representations of disability, as well as lay beliefs and practices, affect the participation or the rejection of persons with disabilities within the family and the community in different cultures. These beliefs relate to what persons with disabilities are expected to achieve, and what they can hope for. Beliefs and assumptions can enable or prevent persons with disabilities from having high self-esteem and confidence for the future.

In Afghanistan, when non-physical reasons for the cause of disability (e.g. 'it is my destiny') were stated as the first answer, the respondent clearly indicated beliefs regarding the cause of his/her condition that were based on cultural and religious norms. These beliefs are particularly widespread in Afghanistan, and have also been described by other authors [36-37]. Similarly, 21% of respondents in the Cambodia study attributed disability to religious causes

(‘karma’). Cambodians are predominantly Buddhist, and so often subscribe to a belief that events in current time are associated with events that occurred in past lives and/or to ancestors [38].

In addition to traditional ethnic and religious beliefs, perceptions of people with disabilities in Afghanistan differ according to gender and roles/events associated with the disabling event. In other words, people with disabilities are not viewed as a homogeneous group, but represent various sub-groups with different needs and opportunities. For instance, being a woman with a disability compounds disadvantages associated with gender and disability [39]. On the other hand, men with disabilities associated with war are valorized, as they are considered courageous and having sacrificed for their country [37]. These war heroes are socially visible (more so than in many other cultures), and they constitute a politically influential group – quite different than other people with disabilities in Afghanistan who experience societal discrimination. Although the distinction is less pronounced in Cambodia, we note that those disabled in war (from previous decades), belong to the only group in the country who have access to special rehabilitation programs, cash benefits and a voice in the Ministry of National Defense. It is clear that the perceived cause of disability has an impact on treatment and status in society, and that cultural views color attitudes and behavior toward those with disabilities.

### *School participation*

Both surveys indicated low school attendance rates, which are of course inconsistent with the goal of ‘Education for All’ [32]. Children who became disabled when they were younger than school age were often at risk of never attending school at all. On the other hand, children who became disabled once they were already in school had difficulty with retention and completion. The authors in the two countries found that 45% and 64% of the children with disabilities respectively in Cambodia and Afghanistan were not attending school.

Moving beyond the crude attendance rate, we then wanted to know *why* the children with disabilities were not starting and/or completing school. The answer to these questions was of interest and concern in both studies. We asked parents or children to report their understanding of why their child did not attend school, and a wide range of reasons were given. In both cases, some of the reasons were described in terms of physical, social and cultural environmental barriers (resources for learning, building access, teacher attitude etc.), and some focused more on the child's impairment (blindness, pain, poor attention span etc.) as causal. Fortunately, the authors had asked respondents a number of questions clarifying both level of impairment (using a scalable framework) and environmental factors for each household. Based on this information, key barriers to school attendance could be identified: lack of physical accessibility for children who used wheelchairs or trolleys; inadequate resources (such as needed adaptive equipment to compensate for poor vision or hearing); parents' low expectations regarding their disabled child's abilities; negative attitudes of teachers and other children towards some, but not all disabled children; socio-cultural barriers such as stigmatisation of certain types of disabilities; and especially in Afghanistan, beliefs concerning girls' education [40]. This was especially true in rural areas, as traditionally access to education for girls has always been mainly an urban phenomenon [41]. In some cases in Afghanistan, the problem seemed to be more global – there just were not schools available for any children in the village.

The fact that there are inadequate practical accommodations needed to ensure children with disabilities access to school explains exclusion for *certain* types of body functions and activity limitations (e.g. a physically inaccessible building will always limit participation of children in wheelchairs). However, cultural perceptions also explain some of their absence. The high level of exclusion for children with epilepsy is probably linked to the Afghan belief that people with epilepsy are possessed by a djinn or spirit [31]. Similarly, "Mayub" (persons who became disabled associated with congenital factors, birth accidents, disease,

malnutrition, or anything that occurs in the first few months of life), are believed to have received a curse from God or to be victims of black magic – thus they are also shunned. In contrast, the “Malul” (those persons who became disabled in association with an accident from war, mine, or car crash), attend school more frequently. In addition, the fact that more girls with disabilities were not in school indicates that gender discrimination is an additional barrier that must be considered.

In Cambodia, some reports have described the impact of stigma and discrimination on community and school participation for persons with disabilities [42]. Although Buddhism emphasizes the value of tolerance and generosity, the belief in karma (suggesting that disability is the outcome of bad deeds in a previous life or by ancestors) may negatively affect perceptions of persons with disabilities [43]. At least one study reports that children with disabilities are teased and called pejorative names [44]. Some parents in the current Cambodian study did indicate that they did not send their child to school because of concerns about these types of issues. However, we found that responses to a general set of questions concerning how people with disabilities should be treated overwhelmingly indicated support for school attendance and other activities considered important to a full, socially involved life. Parents did not report that their children’s disabilities were a reason for non-attendance at school in the same way that parents in Afghanistan did. In fact, when asked directly, people reported that karma might explain why a disability occurred, but that it did not negate the importance of helping people with disabilities to achieve quality of life in the here-and-now. We do not know whether these more open attitudes in Cambodia represent a shift in recent years, or have been there all along, but they are encouraging.

Detailed information on general school attendance data for children, associated with knowledge about activity limitations and environmental barriers (as described in the ICF) allow for a clear determination of what is needed in terms of

policy and programmatic changes to foster better student school involvement, especially for girls with disabilities. Results from both of our surveys would allow school administrators, policy makers, and program developers to identify strategies to improve school attendance of children with disabilities. A comprehensive survey concerning participation of children with disabilities in school must ask a wide range of questions that go beyond basic rates of attendance in order to be useful. The kinds of ICF-based questions that are important include: What types of impairments are most limiting and why? What other personal characteristics (e.g. gender or age) affect participation? What other environmental factors (e.g. rural versus urban, school design, use of universal design such as ramps or wide doors) make a difference and why? Do the children have access to needed assistive devices for specific types of impairments such as visual or hearing loss? Do the teachers have adequate training to teach children with special needs? Is there transportation to get the children to school? Are there prohibitive financial costs involved for parents? What are the attitudes of parents and teachers toward education of children with disabilities? What are the hidden barriers (e.g. cultural beliefs) that are having an impact on schooling participation? Adapted and sensitive questioning based on the ICF help to clarify the range of questions that must be asked. Some of these questions were asked but some questions would require further elaboration to get full information.

Our studies suggest that basic educational and health services are obviously essential for improving the living conditions of children with disabilities, and our studies suggest that sometimes fairly simple and inexpensive solutions could have helped (e.g. reading glasses for children with low visual acuity or awareness training of teachers).

## **Conclusions**

Using the language of the economist Amartya Sen [15], we argue that disability research should assist people with disabilities to expand their capability to



participate and enhance their freedom to make choices. It will be critical to have significant participatory involvement of people with disabilities in the development of research tools and studies. In both the Afghanistan and Cambodian studies, people with disabilities were involved, and their perspectives were often key to identification of research methods and questions associated with collection of important data. For example, in both studies, the decision to avoid asking about “disability” and instead to focus on “difficulty with activity” was based on input from persons with disabilities who knew from experience that the language of “disability” in and of itself could bias responses.

Interestingly, for disability research to be useful, it is also important to know the type of impairment a person has, because required environmental modifications are responsive to certain types of impairments. This flies in the face of the current tendency to minimize impairment discussion as overly medical or labeling. But children who don't go to school because they cannot enter the front door in their wheelchairs face different barriers than children who are blind. In addition, impairments need to be measured using scalable responses whenever possible [34], in order to further clarify resource and policy implications and needs. Simple measures can sometimes be taken to overcome disabling situations. For example, providing reading glasses to children with mild to moderate visual impairments (identified as a need in the Cambodian study) could make a huge difference in assuring school participation. On the other hand, it is rather more complex to address the needs of children who are completely blind, requiring special technology and training for teachers as well as children. And none of these strategies will make a bit of difference for the children who have perfect visual acuity but lack the ability to climb stairs at the entrance to school. Finally, we need to remember that there must be cultural and societal value placed on assuring education for all children, or else all of the accommodations in the world will fail.

In both studies, we found that the ICF shows promise as a model to help guide disability research in a manner that is both sensitive and useful. Simple measures of disability prevalence may be seductive, but lack utility because they cannot capture the complexity or nuances of the construct we refer to as “disability”. It will be useful to develop measurement instruments that can be used to some extent across regions, countries and cultures, and the ICF appears to be capable of providing such a framework. However, in comparing the results of our two surveys, we conclude that to some extent it will probably always be necessary to adapt survey questions to local cultural conditions and contexts [45].

In summary, we can say from experience that the multi-dimensionality of disability, the cultural nuances, and the subtle interplay of factors that come together to create disability are difficult to capture in surveys. But the work is critical to the lives of those who live with disabilities, so we will continue to develop the tools and methods that bring clarity and guide action that is consistent with an understanding of development as freedom for all.

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