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Caring for people with intellectual disabilities in poor rural communities in Cambodia: experience from ADD International

Sylvie Cordier

The burden of care for a disabled relative traditionally falls on women: mothers, wives, sisters. In Cambodia, Khmer culture is strongly structured around the family unit within which both the role of women and discrimination towards people with disabilities are sanctioned by social hierarchy, perceptions of weakness, and the concept of karmic merit. This article explores the impact of ADD International's project in Cambodia to support people with 'intellectual disabilities' – that is, learning disabilities – and aims to assess how this work affected carers, the majority of whom were women.

Le fardeau des soins dispensés à un parent handicapé est traditionnellement porté par les femmes: mères, épouses, sœurs. Au Cambodge, la culture khmère est résolument structurée autour de l'unité familiale, au sein de laquelle tant le rôle des femmes que la discrimination à l'encontre des personnes handicapées sont sanctionnés par la hiérarchie sociale, des perceptions de faiblesse et le concept du mérite karmique. Cet article se penche sur l'impact du projet mené par ADD International au Cambodge pour soutenir les personnes « intellectuellement handicapées » - autrement dit présentent des difficultés d'apprentissage – et a pour objectif d'évaluer l'incidence qu'a eu ce travail sur les personnes chargées des soins, dont la majorité sont des femmes.

Tradicionalmente, la carga de cuidar a un pariente con discapacidad recae en las mujeres: madres, esposas, hermanas. En Camboya, la cultura jemer está estructurada fuertemente en torno la unidad familiar en la que tanto el rol de las mujeres como la discriminación hacia las personas discapacitadas son respaldados por la jerarquía social, por las concepciones respecto a la debilidad y por el concepto de mérito kármico. El presente artículo examina el impacto generado por un proyecto implementado por ADD International en Camboya, el cual se orienta a apoyar a personas con "discapacidades mentales", es decir, con discapacidades de aprendizaje, intentando identificar de qué manera este trabajo afecta a los cuidadores, cuya mayoría son mujeres.

Keywords: carers; people with learning disabilities; Cambodia; women; gender; social stigma; disability

Thida¹ is a 25-year-old woman with learning difficulties, the second of six children. She lives with her widowed mother in a village in Kampong Speu province in Cambodia. She was unable to manage her own care or to participate in the home helping out with household chores. She was scared of having contact with other members of the community and used to wander in the forest on her own, even at night. Her mother was constantly worried for her security, while neighbours used to judge her as stupid and a burden to her family.

This article discusses care for people like Thida, who have learning disabilities, in Cambodia. It raises issues relevant to other societies in which resources are scarce and caregiving has traditionally been assigned to women as a responsibility. Currently, the responsibilities of families (and the women within them), communities, governments, and non-government organisations (NGOs) in caring for children, the elderly, and people with disabilities or health conditions are attracting the attention of policymakers all around the world. Programmes and projects are attempting to address the problems faced by families in ensuring care for these individuals, which does not only include one-to-one care work but also the critical work of provisioning for the entire family – a balancing act which is often almost impossible, leading to poverty for families with high dependency ratios.

This article focuses on 'Helping 157 People with Intellectual Disabilities in Cambodia to Help Themselves', a project which aimed to support communities in Cambodia to learn more about persons with intellectual disabilities and support them in their daily life. It was implemented by ADD International.² For three years, the project worked with main carers, families, communities, and support groups in the five provinces of Kampot, Svay Rieng, Kandal, Kampong Chhnang, and Takeo.

ADD International works from a social and human rights perspective. As such, supporting disabled women to fight for their rights is one of our areas of focus. However, we are yet to capture and evidence the impacts, positive and/or negative, of our interventions on the whole household and the community, and demonstrate how it fits in the wider fight against injustice and poverty. The project was not developed from a gender perspective, nor did it specifically set out to look at the impact of caring on the carers. Instead, it focused on the well-being of people with intellectual disabilities. Yet with most caregivers being women and with a higher prevalence of disabilities among women themselves, we felt it to be important to analyse the experience of (women) carers and people living with disabilities (over half of whom are girls or women), as two socially and economically marginalised, and hence vulnerable, groups. This article examines some of the key insights we gained in the course of the project.

Care-giving: the human rights and development perspectives

The vast majority of care work in countries of the global South is undertaken on an unpaid basis within the family and community. Public services are needed which support, complement, and sometimes substitute for care work provided free within the home, or paid for privately by the wealthier in society. The right to care of disabled people is recognised in the United Nations (UN) Convention on the Rights of Persons with Disabilities (United Nations 2006), signed by all countries and ratified to date by 145 countries, and it stipulates in Paragraph x of its Preamble that 'persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities'. Article 16 of the Convention adds that 'States Parties shall also take appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender and age-sensitive assistance and support for persons with disabilities and their families and caregivers'.

However, particularly in many countries of the global South, access to health services, education, and social protection is not guaranteed by the state. Families with a disabled child or adult are under particular strain, as care work is often more onerous and time-consuming, and can potentially continue over the whole lifecourse, rather than being confined to a limited period during the first or last years of somebody's life. Resources to support the care of disabled people are typically lacking, and delivery systems are rarely in place.

The issue of care provision for people with disabilities is not only a critical issue, but becoming more so over time. In 2002, the World Health Organization (WHO) estimated that the need for long-term carers will grow by 115–257 per cent in developing countries (with some figures of up to 400–581 per cent in some countries) by 2050 (World Health Organization 2002, 16). Although these figures relate to all people who will need care due to disability, ageing, chronic diseases, HIV/AIDs, etc., it is estimated that a high proportion of these carers will support disabled people. In 2011, the WHO and World Bank published a long-awaited report on disability, the *World Report on Disability*, in which it is estimated that more than one billion people live with some form of disability worldwide, with a higher prevalence in low- and middle-income countries, especially among vulnerable groups,³ and around 110–180 million experience significant difficulties in functioning (World Health Organization/World Bank 2011, 29). These figures are likely to increase in the coming decades, due to the ageing of the global population (since, over the course of a lifetime, an individual is more likely to become disabled in some way), and also if extreme climate change events and conflicts increase the numbers and/or proportion of disabled people further.

The impact of caring for a disabled person on household poverty in the global South

Very little research has been carried out on the impact of caring for a disabled person in developing countries. However, the links between household poverty and disability have long been argued. Clearly, households which have disabled family members have particular economic demands on them which other households do not. The WHO/World Bank report on disability refers to the World Health survey data in 15 developing countries, which suggests that 'households with disabled members spend relatively more on health care than households without disabled members' (World Health Organization/World Bank 2011, 39).

In addition, the time spent caring for family members presents an opportunity cost – that is, this time cannot be spent in other activities which may bring in income, or otherwise contribute to the economic stability and welfare of the household. If support services are not available, this increases the time spent in caring, and carers often struggle to take part in any income-generating activities through lack of time linked to the burden of housework and direct care of the disabled person. This condemns the household to continued poverty. There is currently little published research to support these points but they are borne out by ADD's experience in Africa and Asia; we have observed that lack of access to services is detrimental not only to the disabled person, but the whole household. Even less information exists on the health and emotional impacts on carers and their families of supporting a disabled person. Questions that remain largely unasked and unanswered include: To what degree does the main carer experience stress and mental health issues, because of stigma, feelings of hopelessness, and lack of support? How does the stress experienced by the carer interfere with the quality of care provided to the person with disability?

Intellectual disabilities in Cambodia and the work of ADD

It is unclear how many disabled people live in Cambodia. According to the Cambodia Socio-Economic Survey in 2004, 4.7 per cent of the population was disabled (of which 1.2 per cent with learning difficulties), with a high prevalence in rural areas. However, the Asian Development Bank estimates are much higher, at 9.8 per cent. This figure seems more realistic (although some consider it conservative), and in line with the young population structure of Cambodia, linked to the long history of war, genocide, and civil war of the country over 30 years, from 1970 to 2000 (Last and Ken 2009).

As in other countries, disabled people in Cambodia face discrimination and lack of access to basic services. The Cambodia National Assembly passed a Disability Bill in May 2009, and the government ratified the UN Convention on the Rights of Persons with Disabilities in 2012. Yet despite this new legislation being in place, disabled people are continuing to struggle to access basic services such as health, education, transport,

and employment, and to participate fully in society. Obviously a large part of the explanation for this is lack of economic resources to implement the measure required to ensure disabled people receive the services they need.

In addition, disabled Cambodians also face discrimination related to attitudes and beliefs. In Khmer belief systems, an individual's ability 'to positively contribute to the livelihood and well-being of one's family is of the utmost importance. Inability to do so, regardless of the reason, upsets the accepted order and causes friction with the family and society' (Carter 2009, 25). Jennifer Carter (2009) gives a very comprehensive explanation of the complexity of the discrimination towards disabled people in Cambodia, which is linked to 'social hierarchy, karmic merit and the lack of distinction between body and mind as well as a tradition of charity and pity (*ibid.*, 26).

This discrimination is reflected in lack of attention to the interests and needs of disabled people in policies at national level. ADD International has been working in Cambodia for nearly 20 years, supporting disabled people in partnership with the disability rights movement, to be fully included and able to participate fully in society. ADD's Cambodia country programme focuses on capacity building and mentoring of self-help groups, at local level, feeding into and influencing the agenda of disabled people's organisations (at district and province levels), and lobbying for change at policy level. To assist with this agenda, ADD has developed a Participatory Learning and Action tool which it has been using successfully for many years. Its aim is to directly involve disabled people, their families, community, self-help groups, disabled people's organisations, and local authorities in identifying the issues and developing activities which will respond to the interests and needs of disabled people.

In 2007, ADD extended its work in Cambodia to address the exclusion of people with intellectual disabilities,⁴ a group which is subject to particular forms of discrimination and marginalisation within their families and communities as result of their impairment, and which had previously been invisible within the work of disabled people's organisations, self-help groups, NGOs, and government policies. It is likely that the number of persons with intellectual disabilities is even more underestimated than the overall figure for people with disabilities. Intellectual disabilities are not well understood by families, communities, and by the Cambodian government itself. There is general confusion between learning or intellectual disability and mental health issues. In 2011–2012, the Cambodian Ministry of Education with the support of Handicap International conducted an assessment of impairment and disability among 20,000 children and found that one child out of ten is affected by a disability, with a majority related to learning skills.

'Helping 157 People with Intellectual Disabilities in Cambodia to Help Themselves' was started in 2011, after a pilot learning phase had taken place between 2007 and 2009 in two provinces – Kampong Speu and Kampong Chhnang. As stated at the start of the article, this is a project which had a primary aim of supporting communities in

Cambodia to learn more about persons with intellectual disabilities, change attitudes and beliefs about them, and support them in their daily life.

Findings in the pilot phase: poverty, gender, and disabilities

The views expressed during the initial focus groups and various meetings were very negative towards people with intellectual disabilities, who were widely seen as useless, unable to communicate, and a problem requiring families and communities to support them. In the light of the initial findings, ADD identified attitudes to people with intellectual disabilities at the family and community level as being at the heart of the problem – but also, at the heart of the solution.

The participants in our project were all from poor households in rural Cambodia, where rice cultivation is the most important element in family livelihoods. Seasonal requirements for labour in the paddies means people are particularly busy in the fields from June to September in the rice-growing season, and at harvest time from November to March. Additional activities occur parallel to these periods of work on rice, but also take precedence in the two 'low seasons', from March to June, and during October. The activities each household undertakes to augment its livelihood obviously vary, but include vegetable growing, which involves both men and women, and seeking work as a migrant in other districts, which involves men (construction work, taxi, and other labour work) and younger women (garment industry and domestic work) only.

Before the implementation of project activities, women numbered around 80 per cent of main carers for people with intellectual disabilities. Most were mothers. Women are primarily responsible for all care work in the family. During the busy seasons, the women spend time not only farming, but also preparing meals for those who work in the fields, in addition to other tasks of cleaning, water collection, washing, and all other activities. When they have a family member with an intellectual disability, women take on primary responsibility for additional caregiving for the disabled person, often needing to bathe and feed them, as well as keep them safe from dangers.

Traditionally, fathers take care of children when they are older (from seven years old and upwards), and are responsible for enrolling them in school and teaching them to work in the field. They also pass on other technical skills considered essential to raise the family income. It was noticeable, though, that the men did not play an important role in caring for children with intellectual disabilities, even when they passed this age.

Many mothers and fathers of people with intellectual disabilities saw them as a burden and a strain on the family budget. Not only were they not productive contributors themselves, but assigning another member of the family to look after the disabled person meant a loss of labour in productive work. During the term of both phases of the project, mothers expressed their worries about their current ability to care for their children and concern about their future; they were unable to make suggestions

on how to improve their situation. The development needs of people with intellectual disabilities were ignored, and they were often left on their own, leading to loneliness, frustration, and distress, resulting in isolation, low self-esteem, and anti-social forms of behaviour, which compounded the negative attitudes towards them.

The main concern of the parents was that their children with intellectual disabilities needed to be able to care for themselves as well as manage their environment, but there were other major concerns around their behaviour, within the family or the community, including how they engaged with others. There was also a concern for personal security: they were at risk of violence, and in particular carers worried about the possibility of sexual violence directed against girls when outside the home.

It was clear that the ability of the carers to cope was stretched to the limit, and this compromised the care they were able to offer. In addition, like the rest of the community, the carers rarely knew how to support effectively the development needs of people with intellectual disabilities, and most of them did not believe that the situation could ever improve. So, in most cases at the start of the project, they left the people with intellectual disabilities alone, as did other people in the community.

The main project: questions, activities, and findings

The pilot phase had involved discussions of findings on gendered work responsibilities, roles, and schedules, which raised three important concerns for us. First, we wanted to address the level of care that people with intellectual disabilities were receiving during the high agricultural season; there were implications for their current welfare, as well as their future development. We were also concerned about the impact of the additional workload and stresses on the health of the women who were providing the care.

In response, ADD developed a follow-up two-year more extensive phase, targeting people with intellectual disabilities and their families in rural areas. From 2011, the project worked with 158 main carers, families, communities, and support groups in six districts in the five provinces of Kampong Speu, Svay Rieng, Kandal, Kampong Chhnang, and Takeo. The activities of the project were iteratively developed as time went on. We held training sessions and focus group meetings with 311 participants (68 per cent of whom were women) who included 162 people with intellectual disabilities, plus members of their households (usually their main carers), community leaders – traditional and administrative – and representatives of our selected partners, which were disabled people's organisations working at the district level. These training sessions and meetings focused on the issue of intellectual disabilities and the experience of participants living and supporting people with these disabilities in families and within their communities. We used the Participatory Learning and Action tool mentioned earlier for this.

Carers as a specific group were involved in training sessions and workshops about the concept of disability, and the specific issues relating to intellectual disability, and shared their learning with other mothers/caregivers. They also designed practical

interventions, responding to the issues which had come up in the initial phase, and in their own lives and discussions. These included training people with intellectual disabilities about looking after themselves, in particular in areas including personal hygiene, behaving appropriately, ways of earning income and contributing to their families, and ensuring personal safety and security. Capital grants were given to develop income-generating activities to 143 people living with intellectual disabilities. Kids' clubs were created, where children with intellectual disabilities regularly meet and play with toys and books provided by the project.

The ADD team and the disabled people's organisations lobbied the local authorities to recognise the rights of people with intellectual disabilities. They also lobbied relevant development organisations to provide support for access to water and sanitation, including ensuring wells and latrines were constructed close to homes – thus improving not only hygiene but also security for women and girls (with and without disabilities).

Finally, participants including carers were actively involved in ongoing monitoring and evaluation of the project, including collecting Stories of Change.⁵ One of the stories we collected is given below.

A Story of Change: Phalla

Eighteen-year-old Phalla has an intellectual disability and lives in Mepring village, Mepring commune, Batheay district, Kampong Cham province. She is the third child of the family. Phalla did not go to school like the other children in the village. Her family members thought that she was too stupid to study. She did not know how to do housework. She did not know how to cook or even wash herself. She had never been taught to do so. Phalla used to run away from home, she would set off alone and come back in the evening. Phalla's mother was deeply worried about her safety. She told us she had failed to teach her daughter how to do housework. Her daughter knew nothing, she emphasised. No one from the family could get Phalla to do any work. They had a feeling that Phalla liked to be contrary.

The family members, including Phalla's mother, said that they bore negative feelings towards Phalla because of her stupidity. Everyone got angry. Finally, no one took care of Phalla. A self-help group for people with disabilities had been formed in the village. Phalla's mother knew about this but she thought her daughter was crazy so did not think she should join the group. The self-help group did not pay attention to Phalla either. The members of the self-help group were new and had no idea of how to get a person with intellectual disability into the group.

In March 2012, ADD and the Batheay team (a disabled people's organisation in Batheay district of Kampong Chan province) worked with the community people to identify the target group and to plan how to best support marginalised groups. As a result, the project team discovered Phalla and found that she, in common with other women and girls in the village, faced problems of access to sanitation and security. The

project team and villagers agreed that it was risky for Phalla to go out into the forest for defecation, particularly at night and far from the house.

The team helped Phalla's mother and villagers to understand about intellectual disability. They also shared their experiences on how community and family members could help to teach an intellectually disabled person to do simple work. The project team spent a lot of time convincing Phalla's mother to change her way of communication with Phalla. The project provided a toilet for the family. Phalla's mother became active and supported her daughter to raise chickens. She thought that Phalla needed to learn simple activities and skills such as counting, cleaning the toilet, washing herself properly, and so on.

In 2013, the team decided to share the successful outputs with the self-help group members in the village. Phalla's mother had been invited to the meeting of a group of parents of children with intellectual disabilities in January 2013. This meeting affected Phalla's mother profoundly. It changed her behaviour towards Phalla. She found that there are many other people with severe intellectual disabilities. Their mothers could help their children to be more self-sufficient. Phalla's mother then decided to enrol Phalla in the self-help group. Since then, Phalla has been a member of the self-help group of people with disabilities in her village.

Phalla's mother began patiently to teach Phalla cooking, cleaning dishes, and cutting the grass. Through this support, Phalla started to learn and remember better than before. Nowadays, Phalla can bind mosquito nets, wash herself, do her laundry, and get dressed by herself, without being told. Her mother said:

Before my daughter wore clothes for a number of days. She didn't want to change. After being trained by ADD, I learnt that person with intellectual disability needs gentle communication. Now, I have to say sweet words to her, so she can follow my advice and instructions. Now she stopped going out from home [running out because she is upset or simply wandering because she is bored].⁶

Phalla's mother has also made a strong commitment to continue to train her daughter with other skills. She wants to make sure Phalla will increase her self-esteem.

The neighbours have changed their views of Phalla as a result, also, with a wider impact on their attitudes to disabled people in general. Pisey, her neighbour said:

I used to think that disabled person such as Phalla will never be able to do anything by themselves. All the villagers assumed that she was a crazy person and useless. But, now she can make a big difference. (ADD International, Story of Change 2013)

What was the impact of the project?

In this section, I briefly summarise some of the key points from the project evaluation and discussions with the ADD Cambodia director.

Impact on people living with intellectual disabilities

The results of the training of people with intellectual disabilities on self-managing (personal hygiene, care, and social skills) and housework proved very encouraging. All felt they could take better care of themselves. The skills acquired had also ensured new levels of acceptance of people with intellectual disabilities within the family and the community. Through the surveys done during the evaluation, it is evident that acquiring housework skills lightened carers' work. Neighbours and community members described how they had begun to appreciate their potential contribution and to take active steps to include them in the community life, including social events.

The project activities designed to boost people living with intellectual disabilities' ability to earn income were also well-received and appeared successful. There is also a clear indication that the extra income generated by the beneficiaries has positively contributed to improving the economic situation of the families and resulted in improved attitudes towards people with intellectual disabilities within the families and communities: all 143 people with intellectual disabilities trained in income-generating activities had generated income and maintained their project. These ranged from raising chickens, vegetable gardening, hand mat weaving, water vending, motorbike repair to managing a grocery shop; 57 beneficiaries earned more than the original capital grant, while 69 were now able to use their skills to generate an additional income from work in the community (e.g. agriculture) on an ongoing and regular basis, at the normal wage rate and not, as in the past, at an exploitative rate. This result was achieved through the support and mentoring of the project staff and the disabled people's organisations, with a focus on working with the families and the local authority.

Some of the project activities alleviated some of the burden of care from the women, which allowed them to develop/participate more in livelihood activities.

With regard to the issues of personal security which came up in discussions with carers at the start of the project, it appears that carers and families feel their disabled family members are now safer from violence. From the survey data and the numerous Stories of Change collected during the project, we have learnt that now the whole community is relied upon on to deal with issues of personal security. However, the evaluation concluded that progress is still needed in this area.

Impact on carers and caregiving

We were concerned that the project activities were themselves demanding. Participation in the project was a significant activity which added to the workloads of participants, including women carers. In total, involvement required them to devote about one day per week to the project for a period of two years. The feedback was that the participants were satisfied with this as they could see the worth of participating in

these ways. However, not all family members could afford to spare the time to support the activities. In some cases, they were too old or themselves had an intellectual disability.

It seemed that women were more likely to participate than men in the activities of the project. The final evaluation meetings involved all the various stakeholders, but women were disproportionately represented in the focus groups at that time. We did not assume from this that men were not interested in the project and its outcomes as they had been actively involved in on-going monitoring and providing Stories of Change. We think that this may have been due to the fact that the evaluation took place during the high agricultural season, when men were not available to attend due to their tasks of ploughing the rice field and repairing ox carts and other farming tools, and were therefore not as represented in the focus groups as would have been the case during the low season. In discussions with ADD Cambodia staff, men said they also tend not to participate in activities which do not generate some income, unless meeting with high-ranking government officials, which they will not allow women to attend if they can do it themselves.

After the project started, more and more men got involved in training and taking care of people with intellectual disabilities. They were fathers, village elders, and neighbours. One quotation from a village chief who had trained someone with intellectual disabilities to look after pigs expressed his changed views:

In the past, I had no faith in Saran's family. I thought of this family only as being very poor. There are three people with impairment in this family. They cannot earn money as they have no paid job to support them. I did not understand when I saw the Self Help Group implementing the disability awareness-raising project. But, finally they can make a big difference. (Mr Chhim Buth, village chief, who trained Saran to feed her pigs, ADD International, Story of Change 2013)

Carers reported that many of their concerns were alleviated by the acceptance and support they now had from their communities as a result of the project. While some were not completely resolved, carers at least felt that by sharing the issue with neighbours they had decreased their levels of worry.

Some practical wins following the lobbying activities of the self-help groups, disabled people's organisations, and ADD allowed for the official recognition of people with intellectual disabilities through the issuing of government Identity Cards which gives them the right to vote but also importantly gives them access to inheritance rights and are needed in order to be eligible for free health care. Considering that according to health specialists, people with intellectual disabilities are more prone to developing health-related issues, free health care is significant for both the economy of the family and also provides relief for the family in that they now feel able to get support.

Conclusion

There are specific issues faced by carers for disabled people in developing countries. This role largely falls to women. The household is the most important institutional site of care for people with disabilities all over the world, and this is particularly the case in developing countries, where social protection and supportive structures such as day-care centres are usually non-existent, and where inclusive schools (that is, schools which include pupils with disabilities as well as others) are a rare occurrence. This applies particularly in the case of people with learning disabilities – referred to in Cambodia, the focus of this article, as intellectual disability – who come from the poorest families. It is necessary to work with communities, households, carers, and people living with intellectual disabilities themselves to reduce the burden of caring, and to increase the level to which people with disabilities can care for themselves, contribute to the family, and participate fully in society.

Sylvie Cordier is a Research and Influencing Advisor for ADD International and has a strong interest in gender-related issues. She represents ADD International at the Gender and Development meeting and is currently co-chairing the newly created UK Gender and Development Network (GADN) Disability and Gender working group. Postal address: The Old Church School, Butts Hill, Frome BA11 1HR, UK. Email: Sylvie.cordier@add.org.uk

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Notes

- 1 Names have been changed to protect the anonymity of the beneficiaries.
- 2 ADD International was founded as Action on Disability and Development in 1985, to stand alongside disabled people in fighting for positive changes that improve their quality of life. We work collaboratively with disabled people's organisations from grassroots to the global level to change attitudes and policies (see www.add.org/uk).
- 3 In some UN publications, it is estimated that 80 per cent of disabled people live in developing countries, although data are unreliable due to lack of disaggregation in national census and household surveys. On the basis of the majority of the world population living in developing countries and the fact that disability affects the most vulnerable populations, the 80 per cent figure is probably close to the reality. 'Disability disproportionately affects vulnerable populations. Disability is more common among women, older people and households that are poor. Lower income countries have a higher prevalence of disability than higher income countries ... The prevalence of disability is growing due to population ageing and the global increase in chronic health

conditions. Patterns of disability in a particular country are influenced by trends in health conditions and trends in environmental and other factors – such as road traffic crashes, natural disasters, conflict, diet and substance abuse’ (World Health Organization/World Bank 2011).

- 4 While in the UK the most acceptable terminology is ‘person with learning disability or difficulty’, this article employs the direct translation of the terminology used in Cambodia – a ‘person with intellectual disability’, to ensure consistency between the analysis in the article and the quotations which feature in it.
- 5 Stories of Change are stories collected and analysed in the context of a participatory monitoring and evaluation approach to measure the ‘most significant change’ in people’s lives following a development intervention (Davies and Dart 2005).
- 6 The project team observed that people with intellectual disabilities prefer to do what they are familiar with and what they enjoy doing. They often wander because they have nothing to do at home and are not looked after. They often get lost because they cannot make the decision as to whether they should return home or they do not know their way home.

References

- Carter, Jennifer** (2009) *Preparing for the Journey, A Cooperative Approach to Service Provision for Children with Intellectual Disabilities in Cambodia*, Phnom Penh: Hagar
- Davies, Rick and Jess Dart** (2005) *The ‘Most Significant Change’ Technique: A Guide to Its Use*, <http://www.mande.co.uk/docs/MSCGuide.pdf> (last checked by the author September 2014)
- Last, Ulrike and Ratha Ken** (2009) *Disability Facts in Cambodia*, Briefing paper, Lyons: Handicap International France
- United Nations** (2006) *Convention on the Rights of Persons with Disabilities and Its Optional Protocol*, (A/RES/61/106), <http://www.un.org/disabilities/default.asp?id=61> (last checked by the author September 2014)
- World Health Organization** (2002) *Current and Future Long-term Care Needs*, http://www.who.int/chp/knowledge/publications/ltc_needs.pdf (last checked by the author September 2014)
- World Health Organization/World Bank** (2011) *World Report on Disability*, Geneva: WHO