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# Practical lessons from four projects on disability-inclusive development programming

## Sue Coe and Lorraine Wapling

This article considers early lessons learned from the inclusion of disabled people, based on socially inclusive principles, in World Vision programming work in Angola, Armenia, Cambodia, and Senegal. Externally led reviews and evaluations conducted between July 2007 and April 2008 drew out seven key lessons. In summary: the substantial effect of stakeholders' attitudes on practical implementation; the importance of authentic consultation with a range of disabled people; appropriate budgetary considerations; and a need for caution regarding livelihoods work.

## Enseignements pratiques de quatre projets sur la conception et la mise en œuvre de programmes favorisant l'inclusion des personnes handicapée

Cet article se penche sur les premiers enseignements tirés de l'inclusion des personnes handicapées, sur la base des principes d'inclusion sociale, dans les travaux de conception et de mise en œuvre de programmes menés par World Vision en Angola, en Arménie, au Cambodge et au Sénégal. Des examens et évaluations menés par des entités externes entre juillet 2007 et avril 2008 ont tiré sept enseignements. Pour résumer : l'effet substantiel des problèmes attitudinaux des parties prenantes sur la mise en œuvre pratique; l'importance d'une véritable consultation avec une gamme de personnes handicapées; des considérations budgétaires appropriées et la nécessité de faire preuve de circonspection concernant les travaux sur les moyens de subsistance.

## Lições práticas de quatro projetos sobre programas de desenvolvimento inclusivos para pessoas com deficiência

Este artigo examina as primeiras lições aprendidas com a inclusão de pessoas deficientes com base em princípios socialmente inclusivos no trabalho de programa da World Vision na Angola, Armênia, Camboja e Senegal. Revisões externamente coordenadas e avaliações conduzidas entre julho de 2007 e abril de 2008 extraíram sete lições-chave. Em resumo: o efeito substancial de questões de atitude de agentes envolvidos sobre a implementação prática; a importância da consulta autêntica com uma série de pessoas deficientes; considerações orçamentárias apropriadas e a necessidade de cautela em relação ao trabalho sobre meios de subsistência.

## Lecciones prácticas de cuatro proyectos que programan el desarrollo con enfoque para discapacitados

Este ensayo revisa los primeros aprendizajes que obtuvieron los programas de World Vision en Angola, Armenia, Camboya y Senegal, implementados bajo los principios de inclusión social y con participación de personas discapacitadas. Las evaluaciones externas, realizadas entre julio de 2007 y abril de 2008, arrojaron siete lecciones importantes. Algunas de ellas son: los problemas de actitud de los actores tienen un efecto significativo en los programas; es importante consultar las opiniones de una amplia gama de discapacitados; es importante presupuestar adecuadamente; y es necesario tomar precauciones a la hora de implementar actividades que afecten los medios de vida.

KEY WORDS: Gender and diversity; Civil society; Aid; Rights

#### Introduction

World Vision is a Christian relief, development, and advocacy organisation working with children, families, and communities to overcome poverty and injustice. In 2008, World Vision worked in 98 countries, serving more than 100 million people, had 40,000 staff, and an income of more than £1.5bn. World Vision UK is part of this global partnership and has been established since 1982.

World Vision UK has had a Programme Partnership Arrangement (PPA) with the UK government's Department for International Development (DFID) since 2006 which includes an objective to mainstream disability in its work. This does not mean that World Vision is increasing its disability-specific projects; it means that World Vision is actively trying to find ways to ensure that *all* of its work brings benefits to disabled children and adults living in focus communities.

This article seeks to share World Vision's experiences so far of introducing new approaches to including disabled children and adults, based on reviews and evaluations from early projects in four countries. It is written with full recognition that the task is not easy. However, it is now particularly important: in June 2009 the UK ratified the UN Convention on the Rights of Persons with Disabilities, the first human-rights convention of the twenty-first century. This Convention does not relate solely to domestic legislation: the provisions contained within it directly relate to how international development should be conducted. Both Articles 11 (emergency relief) and Article 32 (international co-operation) place responsibilities on all humanitarian and development agencies to be inclusive of disabled people.<sup>1</sup>

#### Changes in perspectives towards disabled people in international NGOs

Disabled people make up between 10 per cent and 20 per cent of any population (Elwan 1999) and are disproportionately represented among the poorest sections of communities. Despite this, active consultation with and inclusion of people with disabilities in mainstream humanitarian and development work is still rare. In developing countries, prevailing attitudes and government policies on disability mean that it is still approached either as a medical issue, with work focusing on initiatives to prevent impairments – or as a charity issue – with interventions created on the assumption that long-term welfare assistance should be the primary response to the needs of people living with disabilities (Lang and Upah 2008).

While some of this work has brought benefits to individuals and can have merits, the underlying assumptions of such interventions are based on perceptions that the individual disabled person is ultimately an unproductive, dependent entity who needs to be 'mitigated' or 'dealt with'. This has led to the prevalence of development interventions based largely on impairment 'needs' assessed by 'expert' personnel, involving specialist services that are often severely limited in terms of geography, age, and impairment. These interventions are generally expensive to run, which deters mainstream aid agencies from including disabled people in their work. It may also partially account for why developing-country governments shy away from incorporating issues affecting disabled people into their plans.

In contrast, the social model of disability focuses on the social exclusion of disabled people (Barnes and Oliver 1993). Its starting place is different from the individual models of disability (medical and charity), explicitly recognising that disabled people are an integral, normal part of society. Disability is the social consequence of a person's having an impairment, i.e. it is society, not the impairment, that disables, through social, cultural, economic, and environmental barriers (Hurst and Albert 2006).

The challenge for development agencies is to apply the social model to its work in countries where the medical/charity approach holds firm. Another major challenge is for them to acknowledge the social-model approach as legitimate and necessary to tackle the poverty faced by millions of people with disabilities worldwide.

## Externally led reviews on disability-inclusion work in Armenia, Angola, Cambodia, and Senegal

In recent years, World Vision has begun to examine what a socially inclusive view of disability means for its work. It is an enormous change, and one which has no established precedent in programming work, either its own or those of other comparable international NGOs. One of the first tasks undertaken as part of World Vision/DFID's PPA was to commission externally led reviews and evaluations to critique early initiatives in four countries:

- **Armenia** support for inclusive education approaches in state primary schools and kindergartens, including advocacy work with the national education ministry.<sup>2</sup>
- Angola a project to support and empower disabled people's organisations (DPOs) to improve their integration into Angolan society, using a rights-based framework.<sup>3</sup>
- Cambodia work to include people with disabilities in three mainstream Area Development Programmes; and to review and alter practices/policies in the central offices of World Vision in Phnom Penh.<sup>4</sup>
- **Senegal** a project in the rural Kolda district to identify and address the barriers facing disabled people locally, in order to increase access to mainstream services.<sup>5</sup>

The reviews and evaluations took place between November 2007 and April 2008. Although these projects were different in nature and conducted in diverse geographical and cultural situations, seven key lessons emerged from them, briefly outlined below.

1 Challenging staff and community attitudes is the key 'first step' to achieving positive progress towards the inclusion of disabled people in development work; early effective training on social-model principles is crucial.

All four reviews resoundingly demonstrated the impact of staff and stakeholder attitudes on project activities and progress towards effective inclusive practices. People's perceptions of

what disability represents (the mental model that they use), cultural beliefs and practices (such as beliefs about what causes impairments), and a deep-rooted fear of how to interact with people with disabilities all contribute to holding back progress on inclusion.

Project staff were largely unaware of the social-model concepts, partly because effective training and clear direction were not provided early enough. This led to project staff continuing to view disabled people as a separate group in need of specialist support. Therefore there was little or no impact on the manner in which work was implemented, and people with disabilities were still not routinely consulted as key stakeholders. A key recommendation from the Cambodia evaluation was that staff and communities in which they worked needed a clearer understanding of the social-model approach. In Armenia, while there were improvements in general attitudes towards the inclusion of disabled children in mainstream classes, it was still seen largely within the context of how medical interventions could be used to enable that to happen. In Angola, training on social-model inclusion happened in the latter half of the project, so it had limited impact because the foundations of work were by then well established.

Cultural beliefs and practices often precluded people from understanding the inclusion of people with disabilities. For example, one review discovered that a pregnant staff member refused to sit in the same room as a disabled colleague, for fear the impairment would be passed on to her unborn child. Progress on inclusion cannot be made until underlying beliefs and prejudices are identified, openly acknowledged, explained, and challenged.

It is still rare to find disabled people in full-time employment in developing countries, so many staff had barely any professional contact with people with disabilities. Many non-disabled staff interviewed in all reviews spoke about the fear of doing or saying the wrong thing. In Armenia that fear led to reluctance by teachers and parents to move forward on ideas for inclusive lessons before 'professionals' could be consulted. Overcoming that fear by focusing on 'system level' changes, rather than on the child's impairment, has since produced very positive progress.

## 2 Old habits die hard: there is a tendency to drift from socially inclusive principles back towards medical/charity-model approaches when implementation starts.

All projects had a tendency to 'drift' back to medical/charity approaches, even if disability-awareness training had taken place. A number of key project staff continued fundamentally to view disability as a medical/charity issue and could not acknowledge that work was drifting away from its socially inclusive intentions. In one case this resulted in project money designated for empowering DPOs actually going to NGOs which clearly still focused on providing services for disabled people. A range of reasons were identified to account for this tendency, with some variation between projects:

- Project staff did not consciously adopt social-model inclusive principles at the outset, so personal attitudes/practices more aligned with medical/charity-model thinking prevailed.
- Staff were not equipped early enough through appropriate attitudinal training to adopt social-model approaches.
- Much NGO work is already medical/charity-model in nature, so socially inclusive approaches were new thinking for some staff.

#### 3 Beware the power of medical professionals!

Medical-model thinking has long been predominant in work with disabled people. Medical intervention has an important place for everyone – but often disabled people are subject to

the views of medical professionals who hold great power and make assumptions about what is best for them. Disability-inclusion work can easily become focused solely on outputs such as rehabilitation, even when there is explicit desire from disabled people not to do so.

For example, World Vision Armenia attempted to break with this assumption and integrate medical efforts within an inclusive education project to ensure that children had access to medical interventions if they were deemed necessary. However, in practice the medical professionals became the dominant force in a project that was originally designed as a tripartite relationship between specialists, teachers, and parents.

There still appears to be a strong emphasis, however, on achieving improved social acceptance and integration through approaches that rehabilitate or 'fix' the individual disabled child, rather than through approaches that comprehensively change the way society thinks and works so that it welcomes anyone who is 'different'. That is, attitude change appears to have been built around a medical rather than social model approach to disability. (Armenia review)

The teachers and parents deferred to the specialists, which delayed progress because there were not enough specialists to cope with the demand. Rather than the teachers and parents working to find solutions to access issues, they tended to wait for professional advice and assume that their own adaptations would not be as good. In effect it disempowered parents and children.

## 4 Consultation with people with disabilities is critical; 'disabled people' are not a homogeneous group, and consultation processes should reflect this.

Many non-disabled people tend to think in homogeneous terms about people who have disabilities. Too often assumptions are made in assessments and reviews about them, rather than undertaking authentic consultation processes involving disabled people.

Further, the label of 'disabled people' covers a broad range of impairment groups (physical, sensory, intellectual, psycho-social) and socio-economic status. As with any cross-section of society, there are also dynamics relating to gender, age, ethnicity, and a multitude of other power relationships.

The projects reviewed tended to receive inputs from a limited range and representation of disabled people – typically, urban-based men with physical impairments. For example, in Angola and Senegal too much emphasis was placed on a small selection of the most articulate and least isolated disabled people, with the result that the impact of the projects was substantially reduced. In Senegal the review found an absence of any representation from people with psycho-social impairments, and in Angola the lack of consultation with deaf people and those with learning impairments resulted in these groups being excluded.

Another general concern was the lack of participation by disabled women. As the Senegal review noted:

Disabled women suffer double marginalisation. They are rejected by men who refuse to get married with them and by their families-in-law who are against their marriage. . . . As a result of these barriers, they remain single or widows, bringing up their children lonely and in extreme poverty.

#### 5 'Practise what you preach': disability-inclusive environments are essential.

Perhaps one of the most surprising results to emerge from the reviews was the lack of attention paid to ensuring that the project environments were as accessible as possible. We came across

many instances where projects were not accessible to many disabled adults or children. For example, the Armenia project was being run from a national office that did not have a meeting room accessible to wheelchair users. In Senegal the reviewers held a stakeholder focus-group discussion with disabled people where it quickly became apparent to them that no sign-language interpretation was being provided for deaf participants, until the reviewers specifically requested it. In Angola no provisions were made for producing any of the project documentation and training materials in large print or Braille format.

Projects which aim to empower disabled people and increase their inclusion in development work should pay particular attention to access issues: for example, training venues should have wheelchair access and local transport links. And it should be borne in mind that many disabled people risk being excluded by the manner in which the training will be delivered: the trainers themselves must be trained in disability awareness; alternative formats for printed materials must be provided, as should sign-language interpretation; there should be regular breaks and variation in activities in the schedule. Participants should be selected from a representative range of DPOs, avoiding over-reliance on just one or two. Project briefings, meetings, and monitoring visits should all be accessible, and the best way to ensure this is to have a small focus group (or steering committee) made up of representatives from across the disability community (think not only about impairment but also gender, age, ethnicity, etc.). Test ideas on this group first, before attempting to engage with the wider disability community.

#### 6 Budget for inclusion — it need not cost much.

One of the main findings from the evaluation of the Angola DPO empowerment project was that insufficient money was allocated to access: for example to hire accessible venues and pay for interpreters, advocates, and personal assistants. This applied to the other projects too.

One of the most common reasons that project staff cite for not including disabled people is the perceived cost. This perception, which essentially stems from medical-model thinking, is not true. For the majority of people with disabilities, small adjustments to the way in which project activities are carried out are all that is needed to secure their involvement: for example, informing people in good time ahead of meetings, taking a bit of extra time to allow for more breaks, producing information in simplified language forms, checking for venue accessibility – things that do not incur significant costs. However, reprinting information in large print or Braille, hiring sign-language interpreters or advocates (for those who are deaf—blind or have moderate/severe learning impairments), covering the costs of personal assistants and guides (for mobility-impaired and visually impaired people), and helping parents to cover the cost of child care will have budgetary implications and will need provision. The key issue is that these should be included at the *design* stage, not once the project is under way, when they are then regarded as 'additional' costs. Evaluations in Cambodia and Angola recommended that funds be specifically set aside for mainstreaming disability issues across the organisation so the necessary adjustments could be made.

## 7 Livelihoods work should be included in mainstream programmes rather than being established as separate initiatives. Analyse barriers and plan very carefully before starting.

Three of the evaluations had livelihood components, in the case of Cambodia a 'sister' project specifically arranging work placements for young people with disabilities. Without exception the projects significantly struggled with this component. It has proved a complex issue, requiring more research, but indications from these evaluations generally showed that

progress would probably be best achieved through mainstream livelihoods programmes specifically examining the barriers excluding disabled people. The main points to highlight here are that, if not handled well, this area of work may increase the exclusion of disabled people; and that doubling up DPOs as income-generating entities confuses the purpose of the DPO and can cause serious long-term problems of internal accountability. As the Angola evaluation pointed out:

The income generating components of this project led to confusion over the project intent and did nothing to ease the tensions, conflict and rivalry caused by competing over resources... It changes the nature of the organisation from being a focal point for lobbying to one providing services.

#### Conclusion

People with disabilities are often the most excluded members of any community, and subject to the deepest poverty. By making explicit the need to include disabled people, benefits will also be gained by a range of other 'hard to reach' socially excluded groups – for example children, older people, pregnant women, and ethnic minorities. By uncovering the mechanisms that exclude disabled people and applying the lessons above, other exclusionary mechanisms will come to light.

These lessons are drawn from early examples of work. There is much more to learn as implementation spreads more broadly within World Vision. We invite you to get in touch and share your own lessons – they would be gratefully received.

#### Notes

- 1. See UN Enable website www.un.org/disabilities for detailed information on the UN Convention on the Rights of Persons with Disabilities (CRPD). For example, Article 11 highlights the need to ensure that *all* emergency and humanitarian aid interventions protect and secure disabled people; and Article 32 stipulates that *all* development programmes have a duty to promote the inclusion of disabled people and to share their experiences and learning.
- 2. Ingrid Lewis (2007) 'Review of World Vision Armenia's Inclusive Education Programme'.
- **3.** Lorraine Wapling, Nsimba Paxe, and John Parkinson (2008) 'Empowerment of Disabled People's Organisations World Vision Angola Final Evaluation Report'.
- 4. Srey Vanthon, Yit Viriya, Cheng Socheat, Ong Kim Lay, Prak Sopho, Trok Moth, Ith Phally, and Sok Sarin (2007) 'Report on the Evaluation of World Vision Cambodia's Disability Mainstreaming Project'.
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