

Disability in Conflict and Emergency Situations: Focus on Tsunami-affected Areas

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Acronyms and Abbreviations

ADB	Asian Development Bank
ADD	Action on Disability and Development (UK IDDC member)
AIFO	Associazione Italiana Amici di Raoul Follereau (Italian IDDC member)
CBM	Cristoffel Blinden Mission (German IDDC member)
CBR	Community Based Rehabilitation
CSO	Civil Society Organisation
DCDD	Dutch Coalition on Disability and Development (Dutch IDDC member)
DFID	Department for International Development (British Government department)
DOJF	Disability Organisations Joint Front (Sri Lankan umbrella organisation)
DPO	Disabled People's Organisation
EDF	European Disability Forum
HI	Handicap International (French IDDC member)
IDDC	International Disability and Development Consortium
IDP	Internally Displaced Persons
IFI	International Financial Institution
INGO	International Non Governmental Organisation
ITDG	Intermediate Technology Development Group
LCC	Leonard Cheshire Centre of Conflict Recovery
LCI	Leonard Cheshire International (British IDDC member)
LFW	Light for the World (Austrian IDDC Member)
LTTE	Liberation Tigers of Tamil Eelam
MoSW	Ministry of Social Welfare
NCPEDP	National Centre for Promotion of Employment Opportunities for Disabled People (India)
NGO	Non Governmental Organisation
PHOS	Platform Handicap en Ontwikkelingssamenwerking (Belgian IDDC member)
PRSP	Poverty Reduction Strategy Paper
SC	Save the Children UK (British IDDC member)
SHIA	Solidarity, Human Rights, Inclusion, Accessibility (Swedish IDDC member)
SIA	Spinal Injuries Association (member of Sri Lankan DOJF)
SSI	Sight Savers International (British IDDC Member)
TAFREN	Taskforce for Reconstructing the Nation (Sri Lankan Government taskforce)
UNDP	United Nations Development Programme
UNICEF	United Nations Children's Fund
UNHCR	United Nations High Commission for Refugees
WHO	World Health Organisation

Glossary

Impairment: An individual's condition – physical, sensory, intellectual or behavioural.

Disability: A complex system of restrictions imposed on people with impairments resulting in a denial of rights and equal opportunities.

Disabled people or people with disabilities: The chosen terminology of the disability movement varies between cultures and languages. In this document we have used disabled people, as this is favoured in the UK. However in other countries the disability movement prefers 'people with disabilities'.

Inclusive Policies: Policies that acknowledge that disabled people have a right to be included in all aspects of an organisation's work and that specific action is needed to counter the discrimination inherent in the way life is currently organised.

The South - used in this document to denote 'developing countries' / 'the majority world'/ economically poorer countries

The North - used in this document to denote 'developed countries' / economically richer countries

Models of Disability:

Medical Model: Disabled people are defined by their impairment and medical/technical solutions offered to alleviate their impairment – an individualistic approach that does not look at social barriers.

Charity Model: Disabled people are to be pitied and helped. There is no recognition of equal rights or the role that discrimination plays.

Social Model: This model sees disability as the social consequence of having an impairment. The inequities faced by disabled people can only be overcome if society becomes inclusive.

The opinions expressed in this report are those of the different authors and should not be taken to represent the views of IDDC or its member agencies. Any factual errors are the responsibility of the authors.

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Executive Summary

The aim

The research was to promote the inclusion of disability in emergency, conflict and refugee programmes. The particular objectives were to assess a) the extent of inclusion, b) the impact of networking and c) the role of resources in post-tsunami contexts. The geographical focus was mainly Sri Lanka, with contributions from India and Indonesia.

The methodology

This was based on a broad framework of principles and approaches, with particular tools being developed by field workers. Principles from emancipatory research were used, such as ensuring that the research fully involved and promoted the rights of disabled persons, together with flexibility and sensitivity required in emergency and conflict situations. The research was underpinned by a social model approach. The core team spent 10 days in Sri Lanka and a day in India conducting the research and also preparing field based researchers to continue.

Although there is extensive literature on the different topics of disasters, disability, development, there has been very little previous research combining these issues, particularly from a social model analysis. From existing literature however, it is evident that disabled persons, particularly in the South, are not fully included, and are amongst the most negatively affected in all aspects of their lives.

The research focused on the post-emergency stage, and a distinction needs to be made between the acute emergency phase that last a few weeks which involves different strategies and resources from the post-emergency phase. Another distinction that needs to be kept in mind is there are those disabled persons and their families who were directly affected by the tsunami, but also those who were affected indirectly, but just as severely.

Context and General Findings

The tsunami is not typical of disasters in many ways. Firstly, there were unprecedented levels of funding and media interest resulting in over-funding in some areas, competition, bottlenecks and pressure to show results. The tsunami resulted in an inverse morbidity and mortality rates¹, as a result of which there is no evidence of a major increase in the numbers of disabled persons. Statistical evidence on numbers of disabled persons affected is vague and unreliable, in keeping with the usual disability and statistics dilemmas. There is however, plenty of recorded testimonies of disabled persons' experience of 'losing everything', which for a disabled person, may mean vital mobility aids, medicines and support structures.

In Sri Lanka and Indonesia, the pre-existing conflict situations exacerbated the impact of the tsunami. In Sri Lanka, the Tamil area of the north were also badly hit and had been waiting years for financial support for basic housing and infrastructure, only to see the post-tsunami aid quickly committed to providing more than was needed for the tsunami affected areas of the Sinhalese south.

The research found inequity in aid distribution in that although the tsunami affected the north-eastern areas of Sri Lanka most severely (mostly Tamil areas controlled by LTTE), the majority of aid and media attention has been focused on the South. E.g. USAID has a policy not to fund work in LTTE controlled areas, and other agencies also favoured the non-conflict areas.

Sri Lanka Stakeholder Responses

The Disability Organisations Joint Front (DOJF) is the umbrella DPO in Sri Lanka. It has been actively campaigning for accessible reconstruction post tsunami, and is a member of two networks focusing on this issue. Its members are also involved in collecting data, facilitating access to aids and equipment, and compiling information on human rights abuses. One women's DPO works in the north Tamil areas. The tsunami provided the opportunity for some city based DPOs to travel to other areas and increase their understanding of poor rural disabled person's situations. Sri Lanka has many residential institutions, one of which received publicity when it was damaged by the tsunami – the conditions were shocking to the researchers, but at least one disabled woman felt that she had more independence there than at her own home, which was inaccessible.

Post tsunami, NGOs and INGOs shifted their priorities to providing emergency relief. Many had policies or stated commitments to include disabled persons, but usually this meant referring them to 'specialist' organisations, or including them as part of a 'vulnerable group' for receiving relief, and sometimes aids and equipment. There was also much evidence that policies had not translated into practice on the ground; OXFAM has published a training manual: *Disability, Equality and Human Rights* and yet was building latrines in Sri Lanka several feet off the ground with no ramps and

¹ Meaning that usually more people are injured than die in a disaster, but in the tsunami, this profile was reversed, as severely injured persons tended to die through drowning.

therefore totally inaccessible. There were several examples of inclusive guidelines and manuals, but the researchers found that these were rarely known about or used.

Disability specialist INGOs are involved in a wide range of activities including general relief and accessible reconstruction, providing emergency medical and rehabilitation facilities, psychosocial counselling, and funding and collaborating with local DPOs. They are also very involved in promoting accessible reconstruction networks (of which there are two).

The Sri Lankan government taskforce on reconstruction, TAFREN has been the source of much criticism and civil society campaigning. Critics say it is being used in an opportunistic way to push through previously unpopular and rejected PRSP proposals, with plans for large scale tourist development requiring the displacement of poor communities, particularly fisher folk.

India Stakeholder Responses

Again, inclusion of disabled persons seems to be limited to surveys, receiving relief and aids and equipment, and does not involve inclusion in planning, decision-making or management. The cumbersome bureaucracy was cited as a major obstacle in post-tsunami relief and rehabilitation, and there were the same issues relating to reconstruction and potential displacement of fishing communities.

The development INGO Action Aid and a local NGO that they fund called Sanghamam, was an exception in its involvement of disabled persons at all levels, and as implementers in relief operations, resulting in an increase in status and confidence of local disabled persons.

Response at International Levels

At the international level, there has been lobbying of the EU, producing positive written response, but in practice, it seems as if inclusion still means delegation to a specialist agency. There is a gap between central level policy and local staff knowledge and understanding. Aid is always affected by political decisions, e.g. the example above of USAID policy.

Most aid INGOs seemed to base their response on needs assessments conducted by IFIs which had not consulted with the community. The research provided an opportunity for DPO members to make a presentation on accessibility to the Asian Development Bank – the strongest lesson was when a disabled woman was carried up two flights of stairs into the inaccessible venue.

Discussion and Analysis

In general, as stated earlier, inclusion did happen but in a very limited way, and not in terms of agenda setting, decision-making, management etc. It was striking that more agencies now use the language of social model and inclusion, but have misunderstandings and do not really apply it in practice. Disabled persons still tended

to be lumped together under the heading of ‘vulnerable groups’ rather than being perceived as rights-holders.

Participation and consultation were also terms that were used freely by larger agencies, but in practice this often still meant just gaining assent for their own agendas. Representation was a key issue – European non-disabled persons often ended up as spokespersons for local disabled persons in fighting for accessible reconstruction. The DPOs had small capacity, were over-stretched, and not experienced in lobbying work, and so bigger agencies felt the priority was to act quickly. This is problematic on many levels. Even within DPOs, the tendency was for the leadership to represent middle-class, highly educated males, some of whom had not even been to the really poor rural areas prior to the tsunami, and so the question of representation of the majority of disabled Sri Lankans was pertinent. Issues are participation and consultation do not just relate to disability however, it is a key issue in emergency contexts in general, given the initial reliance on external efforts to basically save lives and promote survival.

The research highlighted many different and conflicting agendas, and raised the question of ‘inclusion into whose agenda? The focus of the disabled community on accessibility in some ways led to further isolation from other marginalised groups; civil society groups were campaigning against the planned large scale construction of tourist hotels along the coast that would displace poor fishing communities. Disabled access groups were working with these construction groups to ensure that the tourist developments would be accessible. This highlights the debate on the extent to which the disabled community needs to really align itself more with general development issues, rather than staying within a disability ‘cocoon’. It also raises issues about the ‘apolitical’ stance of many INGOs – in a situation where it is impossible to be neutral, and refusal to engage with the wider political issues can result in increased poverty and marginalisation.

Despite the current widespread implementation of psychosocial programmes, mental health issues are still stigmatised. Many people with mental health problems are still being excluded.

Networking and Collaboration

The overall analysis shows that there was strong ‘vertical dominance’ in the linkages, lines of communication and support. In other words the networking was upwards towards those with influence, money and power, with little evidence of horizontal networking, and with the poor communities including disabled people being the least involved and consulted.

Resources

Financial: The tsunami was unique in that it generated unprecedented levels of funding – many larger agencies saying they had ‘too much’ money and didn’t know what to do with it. By way of contrast, smaller NGOs and DPOs were either struggling or failing to access this. There was also an urgency to show evidence of spending the money, which meant that plans were rushed through in popular areas, again

ignoring the community voice. There was also the issue of money being limited to flowing along rigid pre-determined budget lines, thus stressing the need for inclusive policies to be in place beforehand.

Resource Materials: The research found evidence of manuals and guidelines that were inclusive, but did not really see much evidence of them being used to affect practice. Again, they were known about and produced at central levels, but awareness and training had not reached field level.

Conclusion

Inclusion happened to some extent, but not usually at the upper levels of decision-making and planning. There were a range of inclusive resources, but little evidence of them being known or used. Although the language of Inclusion and the Social Model were quite widespread, misunderstanding or ignorance of what this meant in practice was the norm. Representation was a problematical issue, both in terms of European aid workers ending up speaking 'on behalf' of disabled persons in lobbying work, and also in relation DPOs, who often had little direct contact with the majority of poor disabled persons. The huge levels of funding available created many problems as well as offered huge potential. There was little evidence that the money reached poor DPOs or the grass roots, and the pressure to spend quickly didn't support consultation. Campaigns on accessibility were also problematical – in Sri Lanka, the building of totally accessible tourist hotels would result in displacement and disempowerment of poor fishing communities. There was a sense that the disability sector operated within a 'cocoon' and didn't really engage with important mainstream development issues. Networking and collaboration tended to suffer from 'vertical dominance' with poor communities remaining largely 'out of the loop'. In both Sri Lanka and Indonesia, the pre-existing conflict situations were exacerbated by the post tsunami relief efforts. Statistics on disability were as usual problematic, caught in the 'no inclusion therefore no reason to self-identify' loop, and based on an impairment rather than social model. It was difficult to get disaggregated information – there was a tendency to refer to the disabled community as a homogenous group.

Gaps and Recommendations.

- Research, guidelines and training are needed for field staff from a range of agencies on the Social Model and Inclusion and what they mean in practice
- Research, training and awareness raising is needed in relation to Resource Materials and the barriers to their use ?.
- There needs to be more linkages between the disability and the development communities – the disability sector would benefit greatly from engaging more directly with development issues, and of course vice versa.
- The disability sector should consider forming alliances with other marginalized groups and be more aware of the wider political issues
- More research is needed on how local DPOs and other organisations can be strengthened quickly to respond in emergency situations, rather than assuming that international agencies have to take the lead in lobbying
- Research into how representation can be increased when DPOs are still very small and urban based is needed.

- Research in emergency contexts needs to be closely linked to practical programme work, so that people benefit directly in return for sharing information
- More analysis is needed of who undertakes needs assessments and the extent of consultation that has been carried out
- More research into the percentage of tsunami funding that DPOs and local organisations have actually received.
- Agencies need to respond carefully to the current fashion for psychosocial work, and fight against the stigma that persons with mental health conditions face.
- More efforts need to be made to promote horizontal and grass-roots networking and alliances
- Finally, diversity within the disability community needs to be more acknowledged, with differences according to age, gender, class, income, ethnicity etc taken into account.

Part I: Introduction and Background

1.1 Aims and Objectives of Research

The overall aim of this research is to contribute towards the ‘improved inclusion of disability, and improved coordination within programmes responding to emergency/disaster, refugee and conflict situations’. More specifically, the research questions were:

1. To what extent are disabled persons and their families included in the emergency relief and reconstruction operations in Tsunami affected areas, and in other conflict and emergency situations where IDDC members are working?
2. How does networking and collaboration between key stakeholders (DPOs, Governments, UN, donors, NGOs etc) promote the research aim?
3. What existing resources support inclusion in disasters, conflict and refugee situations and to what extent are they being used?

Geographical and Subject focus

Due to the immense impact of the tsunami and the limited resources available, the research focused on 3 affected countries: primarily Sri Lanka, secondarily India, and thirdly Indonesia. Sri Lanka and Indonesia are also affected by long-term conflict.

1.2 Methodology

1.2.1. The methodological framework and principles were outlined in the IDDC Project Proposal and in the Research Prospectus (KaR). Key principles and approaches intended to underpin the research were drawn from emancipatory (e.g. Barnes and Mercer 1997) and conflict/disaster research methodology (e.g. Özerdem 2000). Emancipatory research in the disability context includes the following principles:

- a) The research should help remove barriers and promote the rights of disabled persons, not just passively collect data.
- b) The Social Model should underpin the whole process – people are disabled by society, not by their impairments
- c) Disabled People (from South and North) are the primary stakeholders, designing and conducting the research.
- d) Reflexive and collaborative approach between disabled and non-disabled research coordinators.

In the emergency context,

- e) extreme sensitivity is required in the overall approach and communications
- f) collaboration between all stakeholders should be facilitated

1.2.2. The methodology in practice

The planned methodology had successes and challenges.

Successes include;

- Provoking change: Disabled people presenting their views to international donors. The research raised disability awareness in many agencies
- Social Model and Disabled Researchers: the research was coordinated by a team committed to the social model. The majority of research facilitators were disabled and field researchers were supported to develop their own research tools

Challenges included:

- The emergency situation and short time-scale meant it was not possible to train people fully in participatory research methodology.
- Members of DPOs were fully occupied with emergency work, and although supportive of the research, were unable to take on additional work

1.2.3. Research Itinerary and Key Informants

Members of the Core Team², Rebecca Yeo and Maria Kett spent 10 days in Sri Lanka in February 2005 gathering information and preparing research facilitators. Sue Stubbs spent a day in India working with key field researcher, Shivaram Deshpande to prepare the methodology. Research tools were shared with HI staff in Indonesia who adapted their own tools and conducted a survey. Field researchers in Sri Lanka and India conducted the research in March and April.

Key Informants were primarily from DPOs, INGOs and local NGOs. Grass-roots research involvement was intentionally delegated to field-researchers. The sample size is small and a result of opportunism and key informant contacts. More systematic consultation would require longer-term research.

1.3 Review of Existing Literature

There is substantial literature on disaster and conflict prevention, management and reconstruction, including: the Sphere Guidelines (2004); UNHCR Handbook for Emergencies (1998); UNHCR Resettlement Handbook (2004); the WHO notes on Disasters, Disability and Rehabilitation (2005); and WHO notes on Mental Health in Emergencies (2003). These may help promote protection for disabled people, however they are limited in their promotion of inclusion, and are guidelines, not policy documents. There are few materials covering disability in emergency and conflict situations or the links between poverty, conflict and disability. Where disabled people are mentioned it is usually as a 'vulnerable group', rather than on how barriers to inclusion can be overcome. More work needs to be done to compile a comprehensive literature search (?), which proved to be beyond the capacity of this small project.

² Sue Stubbs, Disability and Development Consultant and IDDC Coordinator, Dr Maria Kett, Research Fellow at LCC, and Rebecca Yeo, Disability and Development Consultant

Part 2: Research Findings

2.1. Context and General Findings

2.1.1. Poverty and Disasters. Communities living in poverty tend to suffer more greatly from natural disasters: they lack early warning systems, have weaker infrastructure and have fewer resources for recovery. The earthquake in Bam, Iran (December 2003), measured 6.6 on the Richter Scale, and killed over 25,000 people; while the 1995 earthquake in Kobe, Japan measured 6.9 on the Richter Scale and killed approximately 5,000 people. The weaker nature of the buildings and the lack of emergency resources in Bam contributed to causing five times the death toll of the Kobe quake

2.1.2. Disability in Conflict and Emergency Situations

IDDC held a seminar on conflict and refugees in 2000. At this event disabled persons living in conflict, refugee and emergency situations indicated that ‘emergency plans are not inclusive or accessible’. The findings showed that many factors contributed to the inaccessibility of relief services: the collapse of basic infrastructures, family displacement, ignorance of disability issues among mainstream relief agencies and the tendency for people to be treated as passive victims (IDDC 2002).

Many people get impairments as a direct result of conflict or disaster situations, or arising from the inadequate healthcare and resources in the post-conflict or post-disaster milieu (Stone1999). The isolation and exclusion resulting from these impairments lead to more people becoming disabled. “Disabled people are often made invisible by society, and invisibility can be lethal in situations of armed conflict or natural calamity.”(Stocking 2003: viii). Past experiences of disaster management shows that disabled people are the most affected group and emergency responses are inadequate to reach out to disabled people (Parr1987). In the aftermath of a conflict or disaster, disabled people may find their situation exacerbated by the loss of family members or carers, moving to inaccessible housing, loss of mobility and other aids, and lack of accessible information, food, water, sanitation and other infrastructure (Edmonds 2005). Disabled people, especially women, are particularly vulnerable to violence, exploitation and sexual abuse (Harris and Enfield 2003). Anyone affected by disasters or conflict is vulnerable to psychological sequelae (MSF 1997), on the basis of which they may be further excluded from the community.

2.1.3. The Tsunami, statistics and disabled people

The Indian Ocean tsunami on 26th December 2004, hit more than 11 countries. Some reported statistics are as follows:

	Dead	Missing
Indonesia	122,232	113,937
Sri Lanka	30,974	4,698
India	10,776	5,640
Total	169,752	127,294

(Compiled from CNN reports

<http://www.cnn.com/2004/WORLD/asiapcf/12/28/tsumaimi.deaths/index.html>)

In many disaster situations, such as the earthquake in Bam 2003, more people are injured than die; however the tsunami caused an inverse morbidity and mortality ratio as more people were unable to escape and drowned.³ Therefore there has not been a significant increase in the numbers of disabled people following the tsunami; however difficulties in accounting for survivors mean an accurate assessment is impossible. In Sri Lanka, the MoSW was trying to compile a database of people with tsunami-related impairments and their equipment needs but this was hampered by lack of staff and more 'essential' relief efforts.

Oxfam and Handicap International (HI), amongst other agencies, have been working to compile registers of disabled people since the tsunami. However, recording the presence of a disabled person does not indicate inclusion. Moreover, inaccurate statistical numbers based only on visible impairments, could back up perceptions that there are 'not that many' disabled people, therefore access issues are not essential. For example, at various meetings attended by researchers, members of the government's Taskforce for Rebuilding the Nation (TAFREN), as well as aid workers claimed there were so few disabled people as to be insignificant.

While there are no accurate statistics as to how many disabled people died or were injured by the tsunami, there are many stories of how disabled people have been affected (see also appendix 3). Many lost their houses, their livelihoods and their belongings, including mobility aids and vital medications. These have cumulative effects:

"I can't remember what has happened. When I regain my consciousness, I was at the Karapitiya hospital. They said they found me unconscious. My diagnosis card and everything has been washed away. But doctors managed to trace my file and gave medication for a week. Since day before yesterday, I didn't have any medication and am finding it difficult to walk. I feel like fainting and can't concentrate. That's why I did not come to your meeting. It is with great difficulty my brother got medicine available in the hospital. For those which are not available the doctors gave a prescription to buy them outside, they are very expensive and where can I find money? Neither does my brother have any. Without that I will not be able to get out of this chair."
Gamini on her experiences of epilepsy, Welfare Centre - Goda Uda
Maha Vidyalaya, Dickwella

2.1.4. Sri Lankan Conflict Situation

³ This is not the same as saying that all disabled people died in the tsunami, which is manifestly not the case.

The civil war between the Sri Lankan government and the Liberation Tigers of the Tamil Eelam (LTTE) came to a tentative end with a peace agreement in 2001.⁴ The sporadic conflict since then has increased in recent months. There are still more than 350,000 people displaced by the conflict, mainly concentrated in the north and east of the island. Conditions are bleak for the 78,000 displaced people remaining in government welfare centres. Both displaced people and returnees often live in dire poverty with limited access to employment, housing, healthcare and education (Global IDP Project 2005). Landmine accidents are common (Landmine Action 2003).

No extra money is provided for housing for disabled people. Most districts have at least one residential institution for disabled people, though residents are officially discharged when they reach 18 years old. Given that there is very little in the way of community support, there is a high potential for homelessness amongst the disabled community.

2.1.5. Tsunami Impact on Conflict Affected Areas

The tsunami hit northeastern areas of Sri Lanka most severely. However, the majority of the aid is focused around southern areas, which are easiest to access and unaffected by the conflict. USAID will not support work in any areas where there is still LTTE activity.⁵ The UNHCR have been calling for relief to cater for all those affected. Frictions between government and LTTE have re-emerged, in part because of tensions about the inequality of relief distribution (Global IDP Project 2005).

While hundreds of thousands of people displaced by the conflict have been waiting for almost 20 years for housing to be reconstructed in the east of Sri Lanka, the enormous international response to the tsunami led to NGOs committing to provide 24,000 shelters in Trincomalee whilst only 8,000 are estimated to be needed.⁶ A similar problem is occurring in Indonesia, where it is claimed that post-tsunami assistance risks neglecting the reintegration needs of conflict-induced IDPs (Global IDP Project 2005).

In the aftermath of the tsunami, people in both Sri Lanka and Indonesia have felt a growing sense of inequality between those affected by the tsunami and those affected by conflict. In Sri Lanka, the UNHCR have called for relief and development efforts to focus on both tsunami- and conflict-affected people. Despite initial collaborative relief efforts frictions between the government and LTTE have re-emerged, in part because of tensions about ongoing needs of people in conflict-affected areas.

The Tamil Relief Organisation provides welfare for Tamils affected by conflict. This organisation has been accused of links with the LTTE. The support received can have a bearing on future allegiances and ultimately, on future peace processes. Therefore some say any rehabilitation programme should take these aspects into

⁴ The civil war in Sri Lanka between government forces and the Liberation Tigers of the Tamil Eelam (LTTE) broke out in late 1980's. The LTTE demanded cessation of areas in the north of the country to the Tamils.

⁵ Interview with USAID representative, Ampara February 2005.

⁶ Meeting of international financial institutions at Asian Development Bank, Colombo, February 2005.

consideration (Boyce 2000). However this is also true of aid from any organisation including government.

2.2. Sri Lanka Stakeholder Responses

2.2.1 DPOs and Disability NGOs

The Disability Organisations Joint Front (DOJF) is an umbrella body with 11 member organisations for disabled people and 8 of disabled people.(?) It is active in the campaign for accessible reconstruction in the aftermath of the tsunami. Despite huge amounts of funding for the tsunami, very little has gone to local organisations such as the DOJF. Many members were unable to give the time to take part in this research because they have to earn a living. At the same time, international agencies have so much funding for tsunami relief they do not know how to spend it.

The DOJF tsunami response can be summarised as follows:

- Information gathering on numbers of Disabled people affected
- Facilitating access to aids and equipment lost during the tsunami
- Compiling reports on human rights abuses of disabled persons in relief efforts: disabled people turned away from relief camps; water and sanitation systems inaccessible within the camps; blind people ridiculed because they cannot find their way around the camps and "mentally retarded" people excluded as they do not know how to use camp toilets.

Particular member agencies have their own tsunami focus:

AKASSA is disabled women's organisation. Members work with disabled people in refugee camps in the north of the country. Akassa provide counselling and training in income generation and empowerment for disabled people, as well as awareness raising courses for government representatives. Many people in the camps became disabled during the war. The camps have international funding, which according to Akassa, discourages people from rebuilding their lives.

According to Akassa the tsunami highlights the injustice between conflict/non-conflict areas. The tsunami was far worse in the northeast than on the south coast, however many people in the north have been living in refugee camps for the past 20 years; hence the consequences of the tsunami are not such a shock. There are high rates of prostitution in the camps as there are few ways of generating an income. AKASSA are keen to use their skills and experience to help avoid similar problems developing in tsunami relief camps, however they lack adequate funds.

Spinal Injuries Association (SIA) provides mobility aids for people affected by the tsunami and others in the northeastern regions. Based in Colombo, the tsunami relief work leads staff to travel to rural areas. SIA staff were appalled by the poverty levels among disabled people, particularly those returning home after years of displacement. These people were often living in far worse conditions than those affected by the tsunami, but had fewer expectations of assistance.

Sambodhi residential home for disabled people, Galle is an institution for disabled people; it is not a member of DOJF. There are many rumours as to what happened here during the tsunami. Some say that 40-50 people died, tied to their beds. Others say many died but no-one was tied to their bed. Whatever the truth is in the manner of the deaths, when international volunteers arrived in the area they were shocked by the state of hygiene and living conditions. The institution received much publicity as volunteers spent months cleaning and refurbishing the home. The residents have a wide range of impairments, ranging from minor eye disorders, to mental health problems, learning difficulties, or mobility impairments.

First impressions of this place were of a dirty, over-crowded institution in which disabled people are hidden from the rest of society. However, one resident reported appreciating the accessibility of the institution in comparison to her own home. After she became disabled during childbirth, her own house became inaccessible to her and she became dependent on her sister. The family are poor and were unable to afford the necessary adaptations to the house or any personal assistance. This woman was taken to Sambodhi, where everything is accessible to her, she reported only needing assistance in hanging out her laundry. She would have preferred her own home to be accessible, but pending this, she reported being glad to live at Sambodhi. There is also a strong sense of community among the residents who clearly help and look out for each other.

2.2.2. Other civil society organisations

A protest against business interests taking priority over ordinary people's needs was organised by the Alliance for the Protection of National Resources and Human Rights (ANRHR), Trade Union Centre for Building the Country and the Free Media Movement. A statement was submitted to government, signed by many civil society organisations and NGOs, but without endorsement from disabled people's organisations (Sri Lanka Development Forum, 2005).

Protesters claim there are remarkable similarities between official reconstruction plans and the Poverty Reduction Strategy Paper (PRSP) 'Regaining Sri Lanka' which the current government pledged not to implement. They call for the disbanding of TAFREN, composed of business representatives, and replacement with a People's Planning Commission composed of representatives of affected communities and experts in relevant fields. They insist that the Joint Mechanism between the government and LTTE is crucial in the processes of rebuilding after the tsunami.

2.2.3. Local and International Development NGOs

Following the tsunami, both local NGOs and INGOs shifted their priorities to providing emergency relief. There are reports of people leaving local NGOs to get temporary employment in INGOs that pay better salaries. Whilst large INGOs have more money than ever before and are offering funding to smaller INGOs, most local NGOs still struggle to obtain funding. Many INGOs differ from local NGOs in that they have some form of theoretical commitment to inclusion. Staff of local NGOs made comments such as 'there aren't any disabled people around here anyway' or 'disabled people make up less than one per cent of the population so their needs are

not so important', whereas staff of INGOs often had all the right language, but in practice, evidence of real inclusion was rare.

Two examples of local NGOs working on conflict recovery issues for many years are:

- Sewa Lanka Foundation (SLF) - one of the biggest Sri Lankan NGOs. It works through local community organisations to strengthen and create social and economic bonds with the poorest and most marginalized groups; this is not however taken to mean disabled people. Any disabled people that are come across are referred on to specialist organisations.
- Family Rehabilitation Centre (FRC) provides training, support and medical treatment for survivors of torture and trauma mainly in the north and east of Sri Lanka. It also works with other NGOs to provide aids and appliances for disabled people

Both FRC and Sewa Lanka receive funding from international organisations and are therefore accountable to them.

INGOs and Inclusion:

- Some claim to include disabled people, but often on the basis of being a 'vulnerable' group rather than full inclusion.
- 'Cash-for-work' schemes are currently the only source of income for many people. Few organisations seem to consider how disabled people can participate.
- MERLIN is working to improve accessibility of health facilities. They requested training from Access for All on how to be more inclusive of disabled people.
- OXFAM UK published a training manual in 2003: 'Disability, Equality, and Human Rights' (Harris and Enfield 2003). However, staff had no specific training in disability issues. Oxfam are involved in building latrines several feet off the ground with no ramps (due to the high water table post-tsunami).

On the east coast they are undertaking assessments in camps to identify the 'most vulnerable'. In one Oxfam office, staff acknowledged that if they came across disabled people in the camps they generally refer them onto specialist organisations (such as HI) rather than include them in their general programmes.

2.2.4. Disability INGOs⁷

Most INGOs work through local partners, and have been involved in the following activities:

- General relief and reconstruction. Identifying disabled persons and responding to their specific relief needs (HI and others). CBM is building 600 accessible houses, in collaboration with DOJF
- Providing emergency medical treatment, rehabilitation therapies, aids and equipment and transport

⁷ HI, CBM, SHIA, Basic Needs and Motivation.

- Surveys and needs assessments. BasicNeeds found that 78 per cent of disabled persons prioritised housing and livelihoods as areas they wanted support for; 90 per cent of disabled persons interviewed had no source of income (see Appendix 1 for full survey results).
- Psycho-social counselling and mental health support. (BasicNeeds, HI, CBM)
- Direct support to DPOs (SHIA), and compiling databases of DPOs (HI). HI has provided 100,000 Euros to fund local DPOs and community disability organisations for post-tsunami programmes.
- Use of existing centres as resource and treatment centres
- Identification and follow up of injured and disabled persons
- Supporting and initiating campaigns for accessible reconstruction in collaboration with DOJF
- Production of inclusive training materials. SHIA coordinated the production of a handbook soon after the tsunami (Swedish Rescue Services 2005).

2.2.5. Networks Lobbying for Accessible Reconstruction

1. **Development with Disabled** has been coordinated by the **Intermediate Technology Development Group (ITDG)** for approximately three years. It consists of 29 organisations, including the DOJF. It aims to combine the disability sector, the development sector and government bodies in order to learn about and improve accessibility. ITDG realise that disabled people are routinely excluded from much poverty reduction work and therefore set up links with DPOs to learn how to reduce the barriers to inclusion. They produced a booklet on the Inclusion of Persons with Disabilities in the tsunami reconstruction process and guidelines for rebuilding including a section on 'disability sensitive planning' (ITDG 2004). Part of ITDG's aim is to encourage other organisations to consult with the community in the disaster relief and reconstruction work. ITDG is one of the few international development organisations to have signed the statement protesting against current reconstruction plans (see 2.2.2.)
2. **Access For All** is a network set up by the UK-based NGO **Motivation** specifically in response to the tsunami. According to their website, their aim is to push for "all public buildings, transport, places of employment, services and infrastructure [to be made] accessible to all. It also means including disabled people in plans for the nation". The focus is on how disabled people can make positive contributions to society if the barriers are removed. They have set up a resource office in the offices of the DOJF in order to give practical advice to aid agencies (See Appendix 2 for a statement from their press conference in March 2005). The network has collaborated with a number of researchers, including Hazel Jones from Loughborough University, who was working on physical access to water and sanitation systems after the tsunami.

Access for All and Development with Disabled are separate networks with similar aims. There has been some collaboration but they are not always aware of what the other is doing. Both include the same representatives from the DOJF. Motivation recruited a disabled Sri Lankan woman to coordinate the campaign, based at the DOJF offices.

Following recommendations made by DOJF and other disability organizations, the Secretary of the Ministry of Education has promised that all new schools will be made accessible.

2.2.6. Government - Taskforce for Rebuilding the Nation (TAFREN)

The relief work is coordinated by the government taskforce, TAFREN. This is composed of 'representatives from the finance, tourism and other business sectors but no-one from the affected areas or from among the public sector professionals, technical professions, or the scientists' (Philips 2005). A worker from a major international financial institution pointed out, (preferring to remain anonymous), "There are clearly vested interests at stake here". Or as a local aid worker put it, "these are the rogues of the nation; they have been stealing from us for years, now they do it under the name of reconstruction". The action plan states that "...the objective is to put in place a new infrastructure and systems to...fulfil the dreams of a modern society" (TAFREN 2005).

Campaigners have pointed out similarities between the TAFREN action plan, 'Rebuilding the tsunami affected area' and the 2002 Sri Lankan Government PRSP (Government of Sri Lanka 2002), officially rejected by the current government. The PRSP called for 'immediate action to acquire the land' for large-scale development of 'high potential tourist areas'. TAFREN's plan includes establishment of tourist zones covering all the coastal tourist areas. These will have "modern infrastructure and...unencumbered view and access to the coast". At the same time a Coastal Conservation (Buffer) Zone is being established, which was planned many years ago but is only now being enforced (TAFREN 2005a). Within this area no damaged houses may be rebuilt, while hotels may be repaired if the costs are below 40 per cent of the replacement value (ibid). In the aftermath of the tsunami, the President declared a state of emergency, which was renewed sporadically in the months that followed (Welikala 2005). It authorised arrest without warrant, detention without trial, limited rights of protest, enabled the police and armed forces to take possession of premises and to forcibly remove people from certain areas.

The rejected PRSP had called for public private partnership in water supply. Having to pay for such an essential commodity as water clearly has potentially devastating consequences for the poorest in the community, including disabled people. In an interview, a representative of the Water Supply and Drainage Sector claimed that less than one per cent of the population are disabled in Sri Lanka, therefore ensuring that water supplies are accessible to disabled people was "not a great concern".

2.3. India Stakeholder Responses

The following categories of stakeholders were consulted: State officials (Government), disability INGOs, development INGOs, national disability NGOs, national development NGOs, DPOs, disabled persons and their families and communities.

2.3.1. Government

India has a National Emergency policy governed by the National Disaster Management Authority, which signifies appropriate measures needed to minimise the effects of conflicts and disasters, and to coordinate, monitor, and review rescue, relief and reconstruction operations. However, researchers found that the state's disaster management information system is ineffective at establishing coping mechanisms, and does not promote the inclusion of disabled people within these operations.

Six officials from the Government of Tamil Nadu departments of Revenue, Emergency, Disability, and General Development were interviewed about policies regarding the inclusion of disabled people in tsunami relief and reconstruction operations.⁸ A number of issues arose that highlighted the lack of coordination and inclusion:

- Inclusion of disabled people in operations was limited to surveying, relief and rehabilitation programmes. All of the officials were aware of the National Emergency Policy and National Disaster Management Authority, but were not aware of any disability component within the National Emergency Policy.
- One of the respondents felt that there was no need to have separate component on disability since relief, rescue and reconstruction is carried out regardless of gender, caste, disability and other factors.
- Officials were unclear whether disability was included or not in any of the existing capacity building exercises and training materials, though they claimed to have tried to involve disability experts in planning operations. Instructions were passed to make buildings and relief camps accessible to persons with disabilities. Necessary assistive devices were distributed for persons with disabilities.
- Persons with disabilities were not involved in the planning or decision-making process.
- Coordination between state and civil society organisations was effective where disability organisations were involved in the planning. But government professionals conducted most disability rehabilitation work.

2.3.2 Indian DPOs, Individual Disabled Persons and Communities

There is a wide range of both single impairment and cross impairment self-advocacy organisations in India. The researchers found no evidence of these national DPOs being involved in tsunami response (see Appendix 3 for individual case studies). A local DPO in Nagapattinam was interviewed:

- It was formed after the tsunami and has more than 1000 members. They work in collaboration with the Union of Construction Workers,
- They have been lobbying donors for assistance for disabled persons, but have been unsuccessful.
- They feel that disabled people have been neglected and excluded from operations, and that only wealthier fishing communities are consulted.

⁸ List of government officials: Officer on Special Duty, Relief and Rehabilitation/tsunami operations, Chennai, Joint Director Disability Department, Chennai, District Disabled Rehabilitation Officer, Chennai, District Collector, Nagapattinam, Additional Commissioner tsunami operations, Nagapattinam

- They are working with poor fishing communities to lobby against re-location away from the coast.
- 36 disabled persons were consulted during focus group discussions. The general feeling (exception in Sangharman communities – see below) was that disabled persons are not included in decision-making, planning, implementing or monitoring and evaluation. Relief is limited to receiving assistive devices and materials.
- Disabled persons feel they do not get relevant information and although development agencies speak of inclusion, it is not the reality.
- Communities felt that they had made efforts to include disabled persons, but that red-tape and apathy are the main obstacles in the relief and reconstruction.

2.3.3. Indian Disability NGOs.⁹

Tsunami involvement included:

- Capacity building of local development agencies on inclusion
- Survey, provision of assistive devices, relief and rehabilitation, creation of self-help groups, access to compensation, psychosocial counselling etc
- These agencies felt that ‘red-tape’, politics and discrimination produced delays in getting the state to fulfil their duties towards disabled persons
- NCPEDP has been lobbying for accessible reconstruction. They found that ‘inclusion’ is misinterpreted and not understood.

2.3.4. Indian Development NGOs¹⁰

Results of interviews were as follows:

- These development agencies do not have emergency policies, nor were they aware of any national emergency policies. They respond to emergencies as necessary.
- Most agencies make no effort to include or exclude disabled people but state that general assistance should not discriminate against disabled people.
- Sanghamam is an agency that recruits disabled volunteers as part of the implementing team. Where Sanghamam is operating, disabled people feel their status has risen in the community. Other groups, such as migrants, are more discriminated against than disabled persons.

2.3.5. International Disability and Development NGOs.¹¹

The Disability INGO response was as follows:

⁹ The following agencies contributed: Cheshire Home (LCI Partner) in Chennai, Joseph Eye Hospital and Gremaltes Hospital – Social Work Departments, and National Centre for Promotion of Employment Opportunities for Disabled People (NCPEDP).

¹⁰ Agencies interviewed: Tata Trust, Salt Foundation, Chennai, Anna Theresa Social Work Association, Art of Living Federation, Sangamam, Stella Mary College, Chennai, Academy for Disaster Management, Education, Planning and Training, Chennai, NGO Coordination Committee for tsunami operations, Nagapattinam.

¹¹ Disability INGOs include: HI, CBM, AIFO and LCI. Development INGOs include: Action Aid, and Peace Federation.

- Survey, relief, medical intervention, lobbying for compensation and accessible environments
- Building capacity and sensitisation of development agencies

Development INGOs:

- Action Aid India has a policy that 10 per cent of total resources should be allocated to disabled people. All capacity building exercises and training materials are inclusive of persons with disabilities. It focuses on inclusion, influencing policy, advocacy and lobbying. Their training manual on disaster preparedness is inclusive
- Peace Federation – disability is a target group but there was little information on what this meant in practice.

2.4. Indonesia

In Aceh, Indonesia, the HI team undertaking this research contacted 15 INGOs¹² and five donor agencies, through a questionnaire survey. The response was weak. The HI team concludes that there are no specific schemes for disabled people nor are measures taken to include disabled people in general relief. HI sent a 'physical rehabilitation ship' to Sumatra immediately after the tsunami and has been actively involved in relief and rehabilitation (see Appendix 4 for details of HI's work). AIFO has a partnership with the Ministry of Health.

2.5. Response at International Levels

2.5.1. Disability INGOs

Lobbying: Several IDDC agencies have been lobbying international donors to be inclusive. IDDC together with the European Disability Forum sent a joint letter to the President of the European Commission and received a reply stating their commitment to including disabled persons (see Appendix 5). ADD sent letters to all members of the UK Disasters Emergency Committee and the Minister for International Development. The CBM office in Brussels has been active in raising awareness on the importance of inclusion with ECHO. A representative of HI spoke to the disability inter-group of the European Parliament on the impact of the tsunami on disabled people (Disability Intergroup 2005).

Training and Resource materials production: ADD contributed to revising the Sphere Handbook (2004) to ensure the inclusion of disability issues. HI produces a wide range of material on accessibility and conflict/emergency related situations. SOURCE (a collaborative project between HI and Healthlink) has produced a 'quicklist' bibliography on Disability, Conflict and Emergencies. SHIA, in collaboration with HI, has been working on producing a Manual on 'Persons with Disabilities in Emergency Situations, and has been conducting training for the Swedish government on integrating disability into their emergency response.

2.5.2. Bilateral Organisations

¹² Including International Organisation of Migration (IOM), Medicine Du Monde (MDM), etc.
Disability in Conflict and Emergency Situations:
Focus on Tsunami-affected Areas
Disability Knowledge and Research Programme

Department for International Development (DfID) (UK) The British Secretary of State at DfID refers to the need for a twin-track approach in the response to the tsunami, as outlined in their issues paper 'Disability, Poverty and Development' (2000). Up to now it has not been possible to discover how this is implemented in practice. He also claimed that 'aid will be delivered according to need and without prejudice on the basis of gender, age or disability'. It is unclear how this takes account of existing discrimination.

USAID

USAID offered financial support to smaller INGOs to work on disability access issues. The danger is that this transfers responsibility for inclusion. One representative on the east coast commented on the lack of local disabled peoples organisations through which USAID could work. USAID will not support any organisations working in areas controlled by the LTTE, irrespective of the extent of the tsunami damage.

2.5.3. Multi-lateral Organisations

European Community Humanitarian Office (ECHO)

The Sri Lankan ECHO office claims to include disabled people in their response to the tsunami. In practice, they are exclusively funding HI to carry out projects on accessibility advocacy, camp accessibility, adaptation of private housing, and awareness raising for community organisations on mainstreaming. Staff interviewed was not aware of the 'European Guidance note on Disability and Development for EU Delegations and Services' (passed in March 2003).

International Financial Institutions

International financial institutions generally provide approximately 70-80 per cent of Sri Lanka's development assistance. By February 2005 the total pledged contribution from IFIs to the reconstruction was US\$410-490 million in a mixture of loans and grants. The total of NGO and public donations are significantly greater than this. However the needs assessment conducted by IFIs still have a major influence on many other donors. The European delegation reported that their plans are based on a combination of the World Bank and the TAFREN needs assessments.¹³ The Access for All campaign is working with the Asian Development Bank (ADB) on their needs assessment.

After contacting the ADB in relation to this research, a presentation on disability issues was arranged at a meeting of the IFIs and bilateral donors. The presentation was made by two disabled women: a resident of the Sambodhi institute and the coordinator of the Access for All campaign. The meeting was held in an inaccessible room and involved one presenter being carried up a flight of stairs.

¹³ See earlier section 2.2.6. The community organisations described above have pointed out the similarities between these two corporate sector approaches and the lack of representation of ordinary people affected by the tsunami.

The World Bank Disability Unit gathers and shares information from active agencies and NGOs about on-going efforts in the various regions as part of relief efforts.

2.5.4. UN Organisations

By their operational mandate, UN organisations should be involved in capacity-building of local organisations, such as the provision of grants, training or advice. These links may extend to DPOs through NGOs, though the research did not find many examples of this happening.

World Health Organisation (WHO)

WHO focuses on health interventions and following the tsunami has produced information about health-related issues, including related to disability (2005b). WHO is limited by its mandate to work through national governments and health services: as one WHO representative interviewed in the northeast stated, only if the government identifies a problem can the WHO work with them to find a solution. He agreed that most shelters are being built without consideration of access needs, however, unless the Sri Lankan government identifies access as a priority the WHO cannot intervene.

UNHCR

UNHCR consider disability a cross-cutting issue with other priority areas such as gender or children, especially in situations of displacement and resettlement. In such circumstances, these groups will be amongst the first to be included in mainstream programmes. In many cases, UNHCR provide immediate relief, then make referrals to other agencies; for example, disabled people are referred on to agencies carrying out CBR work - see UNHCR Handbook on Emergencies (1998).

UNDP

UNDP is the lead agency for livelihoods. There are currently no specific programmes for disabled people. An earlier initiative to work with the Sri Lankan Department of Industry to help disabled people access employment, lacked support and collapsed.

Part 3: Discussion and Analysis

3.1. Inclusion

“Situation analysis on the extent to which disabled persons and their families are included in the relief and reconstruction operations in the Tsunami affected areas over the next few months.” Research Output no. 1

3.1.1. Extent of Inclusion

Indian researchers report that there is general agreement among stakeholders that persons with disabilities are included in relief and reconstruction. But the extent of inclusion is generally limited to distribution of relief materials and aids and appliances. Disability is rarely a priority for mainstream agencies, though Action Aid in India was an example of where disabled people are included at all levels. In general, there was a mismatch between official responses and the reality of limited participation. Overall, the research found little evidence of disabled people being included in setting the agenda or decision-making regarding the tsunami or post conflict reconstruction in Sri Lanka or India. Some agencies include disabled people in emergency relief; this rarely extends to planning or implementation.

3.1.2. Language and Understanding, Policy and Practice

There has been a noticeable change in language used by development agencies in recent years. Terms such as ‘social model’ and ‘inclusion’, are now commonly used. However the research found little evidence that these terms are widely understood or practiced.

“It seems that the majority of development agencies have misunderstood the concept of inclusion - ignoring focussed interventions on the pretext that special attention may result in exclusion. It is the universally established fact that a twin track approach is effective which focuses both specific and general needs of persons with disabilities”. Indian Researchers

All international organisations working on disability and development issues consulted during this research make some mention of commitment to the social model in their promotional materials. Many have policies at central level referring to inclusion. However there appears to be widespread ignorance and confusion as to what this means. The biggest danger is that agency staff (including disability agencies) may be convinced that they are implementing ‘the social model’, or ‘inclusion’ – without realising that they have misunderstood, as so much is invested in maintaining a strong focus on impairments rather than disabling barriers. Language such as ‘crippled by polio’, ‘crawling in the dirt’, and the implication that rehabilitation is the saviour, is found on websites of agencies claiming to operate with the social model. Several agencies just refer anything to do with disability to a ‘specialist’ organisation, and claim to be inclusive. Local organisations tend to have fewer policies regarding disability inclusion, but in the small sample involved in this research the staff were receptive and open to inclusion issues.

This research highlighted the need to question the nature of ‘vulnerability’. In maintaining the notion of vulnerability, are we (the international community) in fact justifying our own actions and interventions? This is not to deny that some sectors of society need more assistance than others, but would addressing issues of rights and equality be a more effective way of tackling ‘vulnerability’?

3.1.3. Consultation, Participation and Representation

The terms ‘participation’ and ‘consultation’ are widely used in the international development sector, however the inherent power issues are rarely acknowledged. The power, status and financial backing of international organisations mean that under-funded local organisations will often ‘agree’ to participate in an agenda which at core is not their own. Moreover, unless local NGOs have a ‘proven’ track record it is often difficult for them to be considered as a serious partnership option by the lead agencies. This does not auger well for relatively inexperienced DPOs. This is not to deny that smaller agencies will often willingly use these opportunities to grow, develop and make influential connections.

Representation is another key issue. The majority of lobbying work for accessible reconstruction is being led by international organisations not by the disability movement. If aid agencies are lobbied by non-disabled Europeans this contact can itself be misinterpreted as consultation with local disabled people. This could perpetuate power differences, if non-disabled people are perceived as speaking on behalf of disabled people it can reinforce the idea that disabled people are incapable of speaking for themselves.

The leadership of DOJF is dominated by highly educated, English speaking men, living in Colombo, who became disabled later in life. These people relate well to the staff of international organisations and government; however it could be questioned whether they represent the needs of poor, rurally based disabled people affected by conflict or the tsunami. Indeed is a poor disabled person affected by the tsunami automatically a representative of others living in this situation, or does representation depend more on being receptive to others views, and specifically being asked to represent them? Debates about representation are not new, there are no simple answers, but the complexity needs to be understood otherwise many people will remain invisible. As researchers in India discovered:

“The need for coordination is of course true in relation to ensuring that the whole disabled community is included, but this is extremely challenging for under-resourced, small-scale DPOs and disability NGOs in an emergency response situation, and feedback from disabled persons in these situations indicates lack of coordination and information sharing, resulting in increased isolation and neglect of particularly vulnerable groups such as those with intellectual impairment, disabled women, and children”

The participants (including the disabled people) in this research can not represent all disabled people. There are gender, age, ethnic, class, and geographical differences.

In addition, in Sri Lanka and in Indonesia, the impact of the conflict may greatly affect people's needs and perspectives.

3.1.4. Inclusion in whose agenda? The Politics of Inclusion

The agenda in which disabled people are to be included rarely seems to be questioned. The World Bank makes great efforts to be seen to be working more inclusively. However, in Sri Lanka, community organisations are demonstrating against the impact that the World Bank and other IFIs are having on the reconstruction agenda (see sections 2.2.6. and 2.5.3). The World Bank agenda, similar to many of the multilateral and bilateral development agencies is based on the promotion of economic growth as the answer to world poverty. This goal leads to success being measured in terms of productivity. Disabled people may be included in this agenda but the vast majority will never be considered fully successful if this is this goal. It is therefore a striking anomaly that whilst many community organisations are demonstrating against the World Bank agenda, the disability sector refer to the change of World Bank rhetoric to mention disability inclusion, as if this were progress.

The huge levels of funding and opportunity for creating a fully inclusive and accessible environment have already been mentioned. But there are conflicting agendas: Herman Kumara, head of the National Fisheries Solidarity Movement in Negombo, refers to the reconstruction in Sri Lanka as "a plan of action amidst the tsunami crisis to hand over the sea and the coast to foreign corporations and tourism, with military assistance from the US Marines." (Klein 2005). The leaders of the tourist sector of TAFREN were keen to establish a dialogue on making the reconstruction of the tourist infrastructure accessible. Whilst fishing communities and their allies¹⁴ are demonstrating against this potential destruction of their livelihoods and construction of a "paradise for tourism and big business" (TAFREN 2005a), the Access for All campaign has been working with TAFREN to push for physical accessibility in the rebuilding of the hotels. If the new tourist infrastructure were to become the first totally physically accessible tourist paradise, what then? How many disabled Sri Lankan's will have financial access to these facilities? Over 90 per cent of disabled Sri Lankan's have an income of less than \$2 a day (Ministry of Social Welfare 2003). Furthermore, how many from among the poorest communities will have lost their livelihoods in the process? The danger is that unless physical access is combined with ensuring financial and social accessibility, then it becomes at best meaningless and at worst gives credibility to policies that are deeply destructive to the wider population.

Those lobbying for disability access may focus so exclusively on disability, at the expense of working with others in similar positions of marginalisation and exclusion, that they are unable to see the bigger picture.

¹⁴. Demonstrations 24 Feb 2005. The Alliance for the Protection of National Resources and Human Rights comprises about 200 people's organisations representing farmers, fisher people, plantation workers, trade unions, women's organisations, human rights organisations, intellectuals, clergy and others. For further details see www.geocities.com/monlarslk

B. Venkatesh, a disabled activist in India has noted:

“I always find I am in a cocoon with similar beings – disabled people and the professionals who work with them. I say ‘cocoon’ because... we insulate ourselves from the outside world. We think, plan and implement campaign issues on disability and nothing else. We are so insulated that we do not see that issues like structural adjustment, liberalisation, global warming etc have grave implications for us. We live in a world of our own....We form, at best, 10 per cent of the world’s population. Much of our problem is from the other 90 per cent. We need them more than they need us.... Our strength is in our numbers: 10 per cent is too small for us to be of any consequence as a vote bank, especially because we are not organised in countries like (*India*). The more we become visible and actively engaged in mainstream development issues the greater is the chance of disability getting on to the agenda of development strategy. Another major reason for such active engagement is to protect our environment and to protect the interest of poor people including poor disabled people” (Venkatesh 2004)

Many aid workers, locals and expatriates, claim to be apolitical in their work. This may be in order to maintain good relations with government, and because of limitations of ‘charitable status’ in some countries. But neutrality is impossible and lack of assessment of the political context can reduce the humanitarian impact. Furthermore, the above example shows how the rhetoric of disability access could be used to give credibility to an agenda which is destructive to the poor community as a whole, including disabled people.

3.1.5. Mental Health and Psychosocial issues

Sri Lanka has one of the highest rates of suicide in the world; possible contributing factors include conflict, unemployment and poverty.¹⁵ Since the tsunami, rates of suicide and of mental illness have become even higher.

It is only since the tsunami that ‘psychosocial support’ has become an issue of widespread concern among NGOs. According to the Consortium of Humanitarian Agencies (CHA), there are currently 45 registered organisations offering psychosocial support compared to 35 offering more general health support. Mental health issues are severely stigmatised, therefore many health professionals differentiate between psychosocial programmes and mental health.

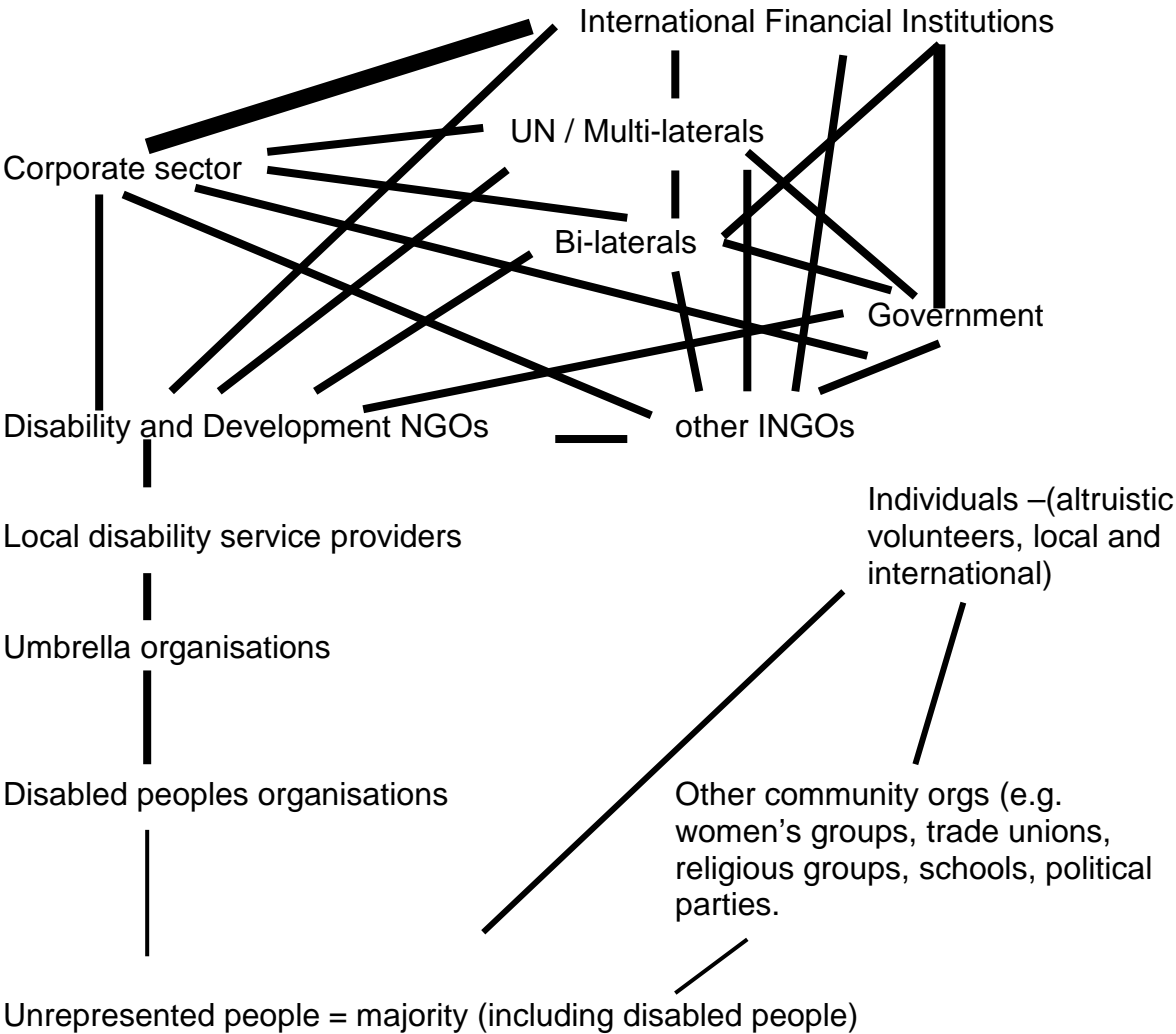
Discrimination on the basis of mental illness is rife. In one hospital visited, a man with a fractured femur was denied treatment due to his ‘mental illness’. The man had a supportive family, and was able to look after himself. However, his consultant felt that to stop his medication to undertake an operation was not feasible. The man was provided with a wheelchair and dismissed.

¹⁵ At least 50 per cent of suicide cases in Sri Lanka are already known to psychiatric services – Interview, President of Sri Lankan Royal College of Psychiatrists February 2005.

One psychiatrist interviewed felt that the tsunami may be a catalyst for the Ministry of Health to improve mental health services. This has included increasing the number of trained psychiatrists and teaching field healthcare workers to identify people who are especially vulnerable. One of the biggest challenges is to prevent the relapse of people with previous mental health problems; these people were overlooked prior to the tsunami, and are likely to be forgotten in the reconstruction phase too.

3.2. Networking and Collaboration

“Analysis of collaboration and networking, highlighting strengths, key players, weaknesses, challenges and opportunities. The research will aim to practically improve effective collaboration and networking.” Research Output no. 2



Vertical Dominance

Evidence from this research suggests the focus of the disability sector is upwards towards those seen as having financial and decision-making power (see chart above). This seems particularly true among those lobbying for accessible reconstruction after the tsunami. There seems to be little horizontal networking with

other people affected by the tsunami but marginalized for reasons other than impairment.

In India, the researchers found a need for better coordination between state, development and disability organisations in order to maximise use of resources and facilitate inclusion. A few disability organisations are working on their own projects in a few tsunami-affected regions. There is potential to involve 600 national/international development agencies to promote the inclusion of persons with disabilities through training and capacity building. Existing communication is ineffective at exchanging information with the grassroots.

3.3. Resources

“Survey and analysis of current resources (policies, manuals, agencies, funding structures etc) that relate to the aim of this research, identifying what works best, why, what could be improved and what the gaps are.” Research Output no. 3

3.3.1. Funding does not create Inclusion

Many of the issues that arose in this research are similar in other contexts. The aspect of the tsunami that is unique is the unprecedented level of funding available. Despite this, a fully accessible/inclusive environment for the whole community is not being created. This exposes the fallacy that disabled people would be included if sufficient resources were available. In Sri Lanka, a government agent reported that when funding reaches local aid workers it is allocated to specific budget lines with no consideration of disabled people’s needs. Therefore, he claimed, if any extra money is spent on making accessible shelters and sanitation systems it would result in fewer being constructed. If this is the case then it suggests that the focus of lobbying needs to be at policy making rather than implementation level.

International organisations argue that the disability movement has weak capacity, and if the lobbying work were to be postponed until disabled people’s organisations are able to take this on independently the buildings will be constructed without consideration of access issues. However, the result may be to postpone the urgent need for funding and capacity building of the disability movement. If the agenda is not set by local people, it can actually become disempowering.

Many international organisations spoke of their current concern about public image. The unprecedented levels of public funding means evidence is needed to prove that the money has been effectively used; otherwise future fundraising may become even harder. On the south coast, where the media readily go, the roads are lined with brightly coloured tents and the flag of the respective donor country. On the east coast, which was far more severely affected, but where the media rarely reach, people sleep under UN tarpaulins. Until disability becomes an issue of widespread public concern it is unlikely to be prioritised where public relations are crucial.

Many people from the bigger international agencies spoke of the novel problem of having so much money they do not know how to spend it. Smaller INGOs that may not have directly received public donations are being offered funding from the larger

organisations. However, there appears to be more reluctance to fund local organisations including DPOs directly.

3.3.2. Training Manuals and Guidelines

Manuals and guidelines that promote the inclusion of disability in emergencies have already been mentioned. The most widely used is probably the Sphere handbook. It is aimed at “improving the effectiveness and accountability of humanitarian assistance”. Much work was done to revise the 2004 edition, incorporating the inclusion of disabled people as a cross-cutting issue:¹⁶

“In order to maximise the coping strategies of those affected by disasters, it is important to acknowledge the differing vulnerabilities, needs and capacities of affected groups. Specific factors, such as gender, age, disability and HIV/AIDS status, affect vulnerability and shape people’s ability to cope and survive in a disaster context. In particular, women, children, older people and people living with HIV/AIDS (PLWH/A) may suffer specific disadvantages in coping with a disaster and may face physical, cultural and social barriers in accessing the services and support to which they are entitled. Frequently ethnic origin, religious or political affiliation, or displacement may put certain people at risk who otherwise would not be considered vulnerable.”
(Sphere 2004:45)

Whilst this is an improvement on previous editions, Sphere has been criticised for its quantitative approach, and “standardising” what are more socially embedded issues such as disability.

In addition, ITDG, SHIA and Oxfam manuals, and EU Guidance Notes have been referred to in earlier sections (2.2.3., 2.2.5, 2.5.1 and 2.5.3). The Sri Lankan government has guidelines on architectural accessibility, as yet unratified. The researchers found very little evidence that these resources were known about, and even less of their use.

Other organisations offer a kind of ‘tool kit’ approach to inclusion, for example focusing on community based rehabilitation (CBR), such as that published by Mobility International (Heinicke-Motsch and Sygall 2004). Some explore specific issues, such as the needs of children with disabilities, models of therapy, treatment and education, and how some of these have been applied where resources are scarce (Zinkin and Mcconachie 1995). HelpAge International (HAI) has prepared guidelines on including older people in emergency relief; many of these issues are similar for disabled people (HelpAge 2000/2001). However, it is debatable whether equipping someone with the ‘tools’ to implement a disability-inclusive programme is the same as giving disabled people equal rights.

¹⁶ However, the 4th edition is not yet available in a number of languages, and given that disability was not mentioned in the first edition, this is a serious omission (Nick Heeren, HI, personal communication).

Part 4: Conclusions and Recommendations

4.1. Conclusions

Overall, the research has been pioneering in attempting to apply emancipatory principles to a large scale disaster situation. It was hampered by the limited time scale, combined with the usual and challenging constraints of conducting really participatory research in an emergency situation. Key conclusions are as follows:

1. **Inclusion** happened to a limited extent, but not at decision-making, upper levels, with the exception of an INGO and NGO in India
2. **Inclusive resource materials** existed, and some were produced very rapidly after the tsunami, but were not generally known about or used.
3. **The language of inclusion and the social model** was widespread, but this has not yet been translated into practice, and was often misunderstood, or used to boost credibility.
4. **Representation, Consultation and Participation.** Representation was problematical in relation to European non-disabled aid workers, local DPOs, and the majority of poor disabled people. The language of consultation and participation was also often used, but in practice powerful agencies gained agreement from smaller agencies for their own agendas.
5. **The surplus finance** available created as many problems as it could potentially solve. There was little evidence of money really reaching grass roots DPOs and poor communities, and the pressure to spend quickly goes against full consultation processes
6. **Accessibility** was rightly prioritised and inspired collaboration and civil action, but due to political agendas, was in danger of becoming 'access for the rich' and further increasing poverty and the marginalisation of the disabled community.
7. **Disability 'cocoon'**. There is a tendency for the disability community to be isolated from civil society campaigns of other marginalised groups, for example, in relation to the accessibility issue. Disabled people frequently lack access to information and are unaware of other campaigns that may be happening, and miss out on mutually beneficial alliances. Many people are campaigning all over the world about reduced access to basic services such as water. The overall reluctance of disability INGOs to also engage with political issues could result in further exclusion and poverty.
8. **Vertical dominance** characterised networking, with the poor community being least consulted and informed, and most of the power, communication and resources being exchanged between northern or bigger agencies.
9. **Conflict/non-conflict divide:** In both Sri Lanka and Indonesia, the post-tsunami funding and politics seem to have exacerbated the pre-existing conflict-induced inequalities, for example USAID refusing to fund organisations working in areas where the LTTE are still known to be active.
10. **Disability Statistics:** the perennial problem of statistics is exacerbated in a disaster situation; where there is exclusion, stigma and no guarantee of services, disabled persons without visible impairments do not want to self-identify, thus perpetuating the myth that 'there are hardly any disabled people'. Statistical research is usually impairment based rather than based on the social model.

11. **Disaggregation.** There is a tendency to treat all disabled people as one homogeneous group. There is a dearth of analysis of the different needs and perspectives of diverse categories of disabled people. The research project was too small scale to gain a full range of diverse perspectives.

4.2. Gaps and Recommendations

1. **Social Model:** More training and support is needed on the social model / disability rights and how it relates to data collection, research, programme planning, implementation and evaluation at field level for local agencies, including DPOs, and international agency field staff. The disability movement could then provide training for international organisations in what the social model means in practice.
2. **Inclusion in Policy and Practice.** More research, guidelines and training are needed to explore and overcome barriers to implementing full inclusion, and to investigate the impact of changes in language and rhetoric.
3. **Resource Materials.** Many different manuals and resources exist for emergency work: some include disability more than others. Research is needed on who is using what, or not, and why and why not? Training and awareness raising are needed at all levels to ensure manuals are known about and used.
4. **Engagement with Development issues** The links between disability issues, general development issues, and other issues of discrimination and exclusion need to be explored and alliances made. For example, the effect of water privatisation on disabled people needs to be examined and links made with others working on these issues. This will create a more powerful and coherent force for lobbying and more genuinely inclusive work. This requires the disability movement and aid agencies to consciously recognise and engage with the political issues.
5. **Effective alliances.** The disability movement need to make clear decisions regarding where to prioritise attention and who to make alliances with. It should not take minor changes in rhetoric as indicators of meaningful change in itself. Similarly being invited to participate should not in itself be taken as an indicator of inclusion.
6. **Lobbying** There is a need to examine the effect on local DPOs and NGOs when INGOs lead lobbying work. More exploration is needed on how local organisations could be strengthened quickly in order to respond to an emergency. Long term funding and training is needed to build the capacity of DPOs in lobbying and campaigning work.
7. **DPO representation** The extent that DPOs represent disabled people who are affected by an emergency needs to be investigated, and also how representation could be increased.
8. **Programme linked research.** Maybe very tsunami specific – but many people complained of the numbers of people coming to ask questions, without giving practical assistance. Important to link research to action/funding/programmes and to be aware of power issues. People are likely to say what they think funders/those with power want to hear, particularly if there is a possibility of funding.

9. **Needs Assessments.** More analysis of who undertakes needs assessments, in consultation with whom and how decisions over allocation of resources are made. DPOs should be involved in the planning and conducting of needs assessments.
10. **Finance:** More work is needed on what proportion of finance and resources have gone to DPOs and local organisations, and a comparison done with situations when there is less funding available. Funding and capacity building support is needed for the disability movement to ensure that it is able to speak on its own behalf.
11. **Development fashion and mental health.** Agencies need to respond carefully to the current fashion for 'psychosocial' interventions, and to be aware of the on-going stigma and exclusion experienced by people with mental illness.
12. **Collaboration and Networking.** More efforts need to be made by all stakeholders to encourage horizontal alliances, and grass roots consultation systems
13. **Diversity:** More research is needed taking account of the diversity of the disabled community, and consulting disabled people of different ages, gender, ethnicity, class, and types of impairment.

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www.worldbank.org/disability

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Part of Reuters, Alertnet provides global news, communications and logistics services to the international disaster relief community and the public. It maintains an international register of aid suppliers; a secure environment in which relief workers in the field can exchange information; databases of training, events, and contacts in the disaster relief community; and background information relevant to disaster relief.

<http://www.alertnet.org/>

ALNAP

The Active Learning Network for Accountability and Performance in Humanitarian Action is an international, interagency forum working to improve learning, accountability and quality across the Humanitarian Sector.

<http://www.alnap.org/>

Disasters Emergency Committee (DEC)

A group of British aid agencies working in international emergency relief which have met certain membership criteria. The DEC supports UK relief sector charities in alleviating suffering among the most vulnerable in major overseas disasters, by:

- providing an accredited national forum to maximize joint fundraising and facilitate a swift response to the disaster
- creating a focal point for the response of the public, the broadcasters and others to such disasters
- facilitating emergency co-operation, co-ordination and communication
- ensuring that funds raised are used in an effective, timely and fully accountable way.

<http://www.dec.org.uk/>

Humanitarian Policy Group Index (ODI)

This group evolved from the Relief and Development Institute, which transferred its activities to ODI in 1991. During the 1990s, the focus of the Group's work shifted from natural disasters to complex political emergencies. The group is re-establishing some capacity to work on natural disasters, but the main focus continues to be complex political emergencies where the operational and policy issues are most challenging for aid agencies. <http://www.odi.org.uk/hpg/index.html>

Integrated Regional Information Networks (IRIN)

The need for an accurate picture of events on the ground is being met by IRIN, part of the United Nations Office for the Coordination of Humanitarian Affairs.

<http://www.reliefweb.int/IRIN/index.phtml>

Red Cross (British)

As part of the International Red Cross and Red Crescent Movement, the British Red Cross assists in the aftermath of natural and manmade disasters. It also works directly with local communities to improve their ability to cope with natural disasters and the 'silent emergencies' of disease and hunger. <http://www.redcross.org.uk/>

Reliefweb

Serving the information needs of the humanitarian relief community. United Nations Office for the Coordination of Humanitarian Affairs (OCHA).

<http://www.reliefweb.int/w/rwb.nsf>

Sphere Project

The Sphere Project aims to improve the quality of assistance provided to people affected by disasters, and to enhance the accountability of the humanitarian system in disaster response. A two-year process of inter-agency collaboration saw Sphere frame a Humanitarian Charter and identify Minimum Standards to be attained in disaster assistance, in each of five key sectors (water supply and sanitation, nutrition,

food aid, shelter, and health services). HelpAge International has contributed extensively to the recent revision of the Charter. <http://www.sphereproject.org/>

VOICE

"Voluntary Organisations in Cooperation in Emergencies" is the largest European network of non-governmental organisations active in the field of humanitarian aid, including emergency aid, rehabilitation, disaster preparedness and conflict prevention. VOICE aims to foster links between these NGOs and to facilitate their contact with the European Union. <http://www.ngovoice.org/>

Appendices

Appendix 1: BasicNeeds Survey Sri Lanka March 2005

Appendix 2: Statement of press conference organized by *Access for All*

Appendix 3: Case Studies from Indian Research

Appendix 4: Handicap International Work in Indonesia

Appendix 5: Response of the European Commission to EDF/IDDC letter

Appendix One: BasicNeeds Survey Sri Lanka March 2005

BASICNEEDS QUESTIONNAIRE TO THE DISABLED PEOPLE

PERSONAL INFORMATION			
Disability			
	Hearing Impairment	2	1%
	Learning disability	36	17%
	Visual Impairment	8	4%
	Mental disorders	35	16%
	Multiple disabilities	19	9%
	Speech impairment	9	4%
	Motor disability	62	29%
	Paralysis	2	1%
	Fits	7	3%
EFFECTS OF TSUNAMI			
Did the Tsunami affect you?			
	Yes	216	100%
If so how?			
	Houses destroyed/ damaged	82	38%
	Lost family livelihood	100	46%
	Family members lost	23	11%
	Lost everything	11	5%
	Furniture washed away	70	32%
	Toilet destroyed	4	2%
	Kitchen washed away	37	17%
	Existing illnesses/ disability worsened	1	0%
	Children's school changed	1	0%
	Confusing the mind	1	0%
	Got caught in the tide	1	0%
	Disabled with a broken the leg	1	0%
	School accessories, books and cloths washed away	1	0%
	Hearing aids washed away	1	0%
Since the Tsunami what has changed for you?			
	Confused and living in fear and grief	43	20%
	Having to live in a new environment	53	25%
	Fear to go near the sea	2	1%
	Helpless and hopeless life	19	9%
	Lost family livelihoods	20	9%
	Living in a shock	3	1%
	Feeling ill and not fit	6	3%

	Had to be dependent on outsiders	18	8%
	Lost all wealth	4	2%
	Come down of health status	2	1%
	Deprive the job	6	3%
	Lack of confidence to return to work	2	1%
	Inclined to the Buddhism	1	0%
	All of are confused	1	0%
	Mother became ill	1	0%
	Lack of medical facilities & food	1	0%
	Sadness from losing the members of the family	1	0%
	Family relationships tightened	1	0%
	Changing the children's school	1	0%
	Hospitalized for 02 months	1	0%
	Fear to live in the home not destroyed	1	0%
	Loneliness due to loosing mother	1	0%
	No place to live	2	1%
	Not expressed	10	5%
	No change	15	7%

NEEDS			
Have you been offered any help?			
	Yes	167	77%
	No	42	19%
If so, by whom?			
	Government	152	70%
	Non Government Organizations	80	37%
	Private sector	27	13%
	Foreign organisations	83	38%
	Volunteer Organizations	1	0%
	J.V.P.	1	0%
	Relations	1	0%
	Buddhist priests	1	0%
What sort of help?			
	Dry rations provided	145	67%
	Money provided	112	52%
	Coupons to buy food	25	12%
	Temporary houses built	17	8%
	Furniture offered	9	4%
	Kitchen tools donated	8	4%
	Cloths	8	4%
	Tents	4	2%
	Educational equipment	3	1%
	Boats	1	0%
	Sanitary ware	1	0%
	Cleaning the premises & houses	2	1%

	Medicine and medical aid	1	0%
	Wheel chairs	2	1%
	Choir machines	1	0%
Is that what you wanted?			
	Yes	51	24%
	No	108	50%
	To some extent	4	2%
Is there anything that would have been more useful?			
	Yes	168	78%
	No	14	6%
	Extra	3	1%

What was your most felt need at the time against what they support you with?			
	To live a way	37	17%
	Permanent house	43	20%
	Fishing nets and tools	32	15%
	Rehabilitate/ re-establish livelihoods for family	27	13%
	Assistance to repair the house	7	3%
	Medical treatment	5	2%
	Restore lost property	3	1%
	Kitchen, furniture and cloths	10	5%
	School equipments	3	1%
	A toilet	3	1%
	Monthly donation of Rs.5000/=	3	1%
	Accessories for disability (wheel chairs, visual aids, hearing aids, etc.,	5	2%
	A land in another place	1	0%
	Sewing machine	1	0%
	Motor bicycle and bicycle	5	2%
	Milk powder for babies	1	0%
	Cash to buy the growth hormone	1	0%
What is your most felt need right now?			
	Livelihood option	66	31%
	Permanent house	63	29%
	Fishing nets & tools	23	11%
	Assistance to repair the house	11	5%
	Assistance for education	4	2%
	Medical treatments, counselling	10	5%
	Kitchen rebuilt	7	3%
	Motor bicycle, Bicycle	6	3%
	Monthly donation of Rs. 5000/=	2	1%
	Hearing aids, clutches, wheel chairs	4	2%
	Furniture and Kitchen utensils	8	4%

	Sewing machine, choir thread machine	3	1%
	A land	3	1%
	Dry rations	1	0%
	Milk powder for babies	1	0%
	Cash to buy the growth hormone	1	0%

FAMILY STATUS

Where do you live now? With whom?

	In the own house with my family	136	63%
	In relations' house with the family	39	18%
	In temporary house with the family	36	17%
	In the Camp with the family and community	3	1%
	In the Camp with the family	2	1%
	In a rented house with wife and children	1	0%
	In temporary house alone	1	0%
	Alone in my own house	1	0%
	In a rented house alone	1	0%

Do you have any income? Of what kind?

	Yes	17	8%
	From brother's job	1	0%
	Child's salary	1	0%
	From business	1	0%
	From trading	1	0%
	Government allowances	5	2%
	Labour work	1	0%
	Income through odd jobs	1	0%
	Pension	3	1%
			0%
	No	195	90%

Does any one in your household have any paid work?

	Yes	26	12%
	No	187	87%

Did you go to school?

	Yes	97	45%
	No	55	25%

Up to what level?

	Up to grade 10	5	2%
	Up to grade 05	19	9%
	Up to grade 09	3	1%
	Up to grade 2	4	2%
	Up to grade 7	2	1%
	Up to grade 3	6	3%
	Up to grade 4	12	6%

	Up to G.C.E. (O/L)	21	10%
	Up to G.C.E. (A/L)	3	1%
	Up to grade 8	8	4%
	Up to grade 6	4	2%
	Up to grade 10	3	1%
	Special school units	12	6%
Do you go to school?			
	Yes	44	20%
	No	11	5%
Which level?			
	Special unit at Godauda Maha Vidyalaya	1	0%
	Special unit at Gandara K.V.	1	0%
	Special unit at Navajeevana	14	6%
	Special unit at Deepankara Vidyalaya	3	1%
	Special unit at Kudawella	1	0%
	Grade 7	2	1%
	Grade 5	1	0%
	Grade 11	3	1%
	Grade 8	5	2%
	Grade 6	5	2%
	Grade 2	2	1%
	Grade 9	1	0%
	Grade 4	2	1%
	Grade 1	2	1%
Do you have brothers and sisters?			
	Yes	138	64%
	No	27	13%
	Died from Tsunami	3	1%
Did they go to school?			
	Yes	60	28%
	No	8	4%
Up to what level?			
	Up to G.C.E. (O/L)	33	15%
	Up to G.C.E. (A/L)	12	6%
	Up to grade 8	9	4%
	Up to grade 10	6	3%
	Up to grade 6	5	2%
	Up to grade 3	5	2%
	Up to grade 5	3	1%
	Up to grade 4	3	1%
	Up to grade 7	2	1%
	Up to grade 2	1	0%

Do they go to school?			
	Yes	69	32%
	No	9	4%
Which level?			
	Grade 5	6	3%
	Grade 9	14	6%
	Grade 1	5	2%
	Grade 8	13	6%
	Grade 7	14	6%
	Grade 6	12	6%
	Grade 2	8	4%
	G.C.E. (A/L)	12	6%
	G.C.E. (O/L)	12	6%
	Grade 3	7	3%
	Grade 4	14	6%
	Grade 10	8	4%
	University	1	0%
	External degree	1	0%

SOCIAL STATUS

Do you belong to any clubs or organizations?			
	Yes	108	50%
	Plan International children's society	1	0%
	Navajeevana Disabled People's organisations	17	8%
	Disabled peoples' organization - Navodaya	20	9%
	Blind people's association	1	0%
	Samurdhi	46	21%
	Funeral Society	4	2%
	Fihasing Society	20	9%
	Sanasa	11	5%
	Association for small fishermen	17	8%
	Rural Development Society	2	1%
	Janashakthi	17	8%
	Women's' Society	2	1%
	Youth Society	1	0%
	Ceylinco Ceylon	1	0%
	Elders' Society	2	1%
	Sarvodaya	1	0%
	Pensioners' Society	1	0%
	Rekawa development foundation	1	0%
	Biodiversity Society	1	0%
	No	90	42%
Do you consider yourself disabled?			

	Yes	108	50%
	No	43	20%
	No comments	50	23%
If so, in what ways does this affect the way people treat you?			
<u>Expression in Yes</u>			
	Community support well	5	2%
	Special attention from community	2	1%
	Sympathy	1	0%
	Negative attitudes	11	5%
	Treat as a normal person	27	13%
	Make fun of us	4	2%
	Positive attitudes	44	20%
	Labelling/ stigma	5	2%
	Benefits not given	3	1%
<u>Expression in No</u>			
	Treat differently to disabled persons	1	0%
	No special attention	9	4%
	Negative attitudes	3	1%
	Special attention from community	3	1%
	Labelling/ stigma	3	1%
	Positive attitudes	20	9%
<u>Not expression</u>			
	Positive attitudes	21	10%
	Negative attitudes	8	4%
	No special attention	6	3%
	Labelling/ stigma	3	1%
Are there anything you would like to do but prevented from doing because of you are disabled?			
	Yes	83	38%
	Repair the bicycles	2	1%
	Fishing Industry	9	4%
	Education	26	12%
	Trading	11	5%
	Choir threads	9	4%
	Repair fishing nets	6	3%
	Sewing	4	2%
	Carpentry works	2	1%
	Drying fish	2	1%
	Animal husbandry	2	1%
	Repair T.V., cassettes	2	1%
	Go to the sea	1	0%
	Making brooms	1	0%
	Astrology	1	0%

	Anything	2	1%
	Dancing	1	0%
	Making the banners	1	0%
	No	73	34%
Do you know other disabled people?			
	Yes	105	49%
	No	15	7%
	Not expression	40	19%
Is there anything else, you would like to tell us?			
	Helps to get a job	10	5%
	School uniforms, equipments and money to go to school	6	3%
	Safer place to live	7	3%
	Equipments for self employment	5	2%
	Assistance to run to the fisheries work	3	1%
	Some grants to revive the retail shop	3	1%
	Money to get medicine	5	2%
	Equipments for improve the business	2	1%
	Tricycle for get earn money	2	1%
	One of the mentally ill people in the family	2	1%
	House to live	2	1%
	Medical treatments and counselling	4	2%
	Milk flour	1	0%
	Sadness from deprive the boat	1	0%
	Choir thread machine	2	1%
	Help to face the economic burdens after husband's retirement	2	1%
	Mother is in abroad	1	0%
	Give spectacles	1	0%
	Daughter is looking for a job	1	0%
	Want the special shoes quickly	1	0%
	Furniture to live the home with alone	1	0%
	As a result of retail trades, increase the mental illness	1	0%
	Cash to buy growth hormone	1	0%
	As a result of the leg disabled, want a Motor bicycle	1	0%
	Boat and nets to have a independent living	1	0%
	Go through the Carpentry work, want a shop	1	0%
	Aid for make a house	1	0%
	Permanent house	1	0%
	Special aid chair and wheel chair	1	0%
	Drug addicted after the Tsunami	1	0%
	Grandfather is ill after the (Tsunami caught the waves)	1	0%

	As a result of nobody, not got the aids	1	0%
	After the mother faced an accident broken the leg	1	0%
	Kitchen tools	1	0%
	Suffering without foods	1	0%
	Sponsorship for living	1	0%
	Lost householder and no grants or donations due to that	1	0%
	Relapses experienced after Tsunami	1	0%
	Will for work as a voluntarily	1	0%
	Need a land to built a house	1	0%
	Want money	1	0%
	After the Tsunami lost three fingers in the hand, physically injured, can't walk, business is fell down, want aids	1	0%
	NO OF SURVEY FORMS	216	100%

**Appendix 2: Statement of press conference organized by Access for All
Galle Face Hotel, Colombo, Sri Lanka.
Wednesday 16th February 2005**

Chaired by Dr. Radhika Coomaraswamy (Chairperson - Human Rights Commission of Sri Lanka)

The Access for All campaign intends to highlight the needs of disabled people in the wake of the tsunami and to promote the inclusion of disabled people in relief, development and reconstruction activities and planning.

A small consortium has been formed with a national umbrella group for disability organisations and disability INGOs to promote this campaign and to open a resource office that will provide support and advice on accessibility.

Despite the unquestionable tragedy of the tsunami, Sri Lanka is now presented with a fantastic opportunity to make a big change in its policies, but perhaps more importantly, in its application of policy. For example, the amount of reconstruction taking place along the coastal belt - reconstruction of public transport facilities, health-care clinics and schools, places of employment and public buildings - provides a great opportunity to rebuild with everybody's needs in mind and consider access for disabled people in all construction.

Sri Lanka has national guidelines already published on architectural accessibility and a national policy on disability for other spheres of life - such as employment and education, and also has the money to do so. Building with accessibility in mind from the design stage should not add any significant cost to construction, and will make the work accessible to disabled people, older people and people with pushchairs for example.

There are approaching 2 million disabled people in Sri Lanka (10% of the population), an accessible environment will allow them to contribute to society and the economy (to attend academic institutions, workplaces, shops); not to mention the opportunity that will arise if places of tourism are accessible, opening a whole new market in Sri Lanka.

In Sri Lanka disabled people are largely stigmatised and excluded from society: families hide disabled members from public view. As a consequence they are often invisible in the community. In an emergency situation disabled people are particularly vulnerable and become even more invisible to Government and international agencies in the delivery of aid and services.

It is vital that information distributed to local communities reaches the disabled population and efforts must be made to ensure service delivery centres, such as health care centres or temporary accommodation, are accessible for disabled people.

We believe that the most effective way to protect a very vulnerable part of the population, as disabled people are in these situations, is to involve disability organisations in the localities concerned to ensure that the emergency response is

inclusive of disabled persons. Therefore, the Access For All office would like to offer their full cooperation and expertise in this respect, as and whenever required.

Appendix 3: Indian CASE STORIES (Contributed by Shivaram Deshpande and Victor Cordeiro)

Detailed reports by Indian researchers are available on the IDDC website (http://www.iddc.org.uk/dis_dev/key_issues/IndiaTsunami_report.doc).

1. Chandra Sekar is a 23years old boy affected by Polio and lives in Kovalam. He has studied upto 9th Standard and looking for a job. He is living with his mother, younger brother and sister. Hitherto, brother was going for fishing as daily wager. The mother (widow) sells fish. The house got damaged during the Tsunami and has no means to live presently.

The family was given assistance in terms of rice and other provisions immediately after the disaster. As part of the Income Generation Support, the family is given a catamaran(country wooden craft), an engine(7hp) and two sets of nets for fishing.

Our focus enabled them to feel comfortable, dignified and element of mainstreaming has been realized. His family was in crisis before our support. Now he is willing to go to sea. He is going to start fishing to support his family. Chandra Sekar says, "I have a sense of independence and contribute to my family".

2. Desapattu is 42 years old orthopaedically disabled person lives with his wife and 5 daughters in Karikattu Kuppam village of Muttukadu and lost his recently bought boat and out board motor in the Tsunami. He has been hardworking and highly responsible person with maturity.

He was supported with monthly provision in the beginning. Later, he was included in the list of beneficiaries for the Boats. His engine was salvaged and repaired with our support. Now, he has got the boat and preparing for fishing. He is one of the potential leaders in our capacity building process

3. Gobu is a 25 years old man belonging to Kovalam village affected by polio. He lives with mother, wife and a small child. He goes to sea with others as daily wager. He is one among the four benefited from us in the village as there was no support was given from the community nor covered under Government. He has been given a Catamaran (country wooden craft), engine and two sets of nets from our relief programme.

He became jobless after the killer wave that struck the village on the 26th December. He and his family members escaped the giant waves by running to the higher grounds. In fact, he was not aware of the Tsunami, as he was fishing and returning after sometime to see his house crumbled and rubbles all over the place.

Gobu says "We would have got nothing but sympathy and little bit of charity, your support will make ways for my livelihood".

They are preparing themselves to go to sea for fishing.

4. Nagooran is a 21 year old young active and energetic boy lives with his parents and other family members in Karikattu Kuppam village of Muttukadu. The boy escaped the disaster by jumping over a wall despite his disability (polio with both the legs affected and confined to Wheel chair) and moves with the support of tri-cycle. He has been highly motivated and confident, hard working and busy with his business of fishing and marketing the fish in the local bazar.

He has been given a boat and engine for his economic development. His medical intervention is under process. The family was provided basic items for cooking immediately after the displacement during December 2004. The family is still living in the temporary shelter set up by the Government four months ago awaiting a decision on a permanent settlement. However, he and his family are preparing for their daily activities to resume a normal life

With our support the family have the feeling of participation rather than a burden. The parents believe that but for our intervention they would not have got anything. "Upgradation of accessories in terms of boat rather than a traditional wooden craft has made us more confident and we will never forget Leonard Cheshire in our life".

5. Jayalaxmi is a beautiful intelligent 21 year old girl with polio. She is studying M.Com and was interested to take up a professional course in Computers course for which she had collected Rs. 14,000/- But now she cannot even continue her education because the tsunami waves have swept away all the money, her books, certificates along with the hut and household articles. She has somehow survived the killer waves along with her mother, elder brother, younger sister and father. But they do not have anything left. As such they were very poor and used to live in a small hut on the beach very close to the sea.

"I was having breakfast with two children related to us. I heard a noise like a helicopter landing and heard people shouting water is coming, sea is coming. I picked up both the children and ran to a cement building close by and rushed to the roof top." Father Kannadasan is a agriculturalist. Jayalaxmi said, "We had half acre land in front of the hut. We used to grow paddy. The crop was ready for reaping when the waves came and swept every thing away. The land is filled with sea water and sand. They say we cannot grow anything on that land for at least three years. I do not know from where my father will pay for my education. We also lost six goats in the waves."

Jayalaxmi is very intelligent and has a bright future. But after Tsunami she had a feeling that her future is dark. She needs support for livelihood and education.

Jayalakshmi is supported under ISRP programme for computer education course called "Honour of Diploma Computer Application". She got admission for the course in a local college by paying the required fees which has been funded by LCI.. Jayalakshmi now says that she is very happy that she got such a good opportunity to join HDCA course, she is eagerly waiting for the opening of the college to continue her studies and her dream got fulfilled. Jayalakshmi along with her family members expressed that they have not received compensation till date from Government and unfortunately no other NGOs have stepped into the area for any

kind of help. Her parents expressed that only LCI ROSA office has provided support to continue their daughter's education and they are very grateful to LCI for the timely help.

6. Sarvanan is a 25 year old boy from Boombugar village and has haemoplaegic disability. He has never been to school. He has one elder brother who is a fishing labourer and a younger sister who is studying in 12th standard and was affected by polio in childhood. Father and brother are the only bread winners in the family. The family is very poor. Sarvanan is epileptic and needs medicines worth Rs. 250/- to 300/- every month. Just a week before the tsunami incident while the family was sleeping in the night a cat jumped onto the kerosene lamp which fell on the father and he suffered from severe burns to his face, eyes, neck, upper arms, upper chest and leg. Mother and brother took him to the hospital and admitted him. It was very difficult to meet the expenses for the treatment. When tsunami hit their village Sarvanan and his sister were alone in the house. They heard the killer waves coming but were unable to run away due to their physical disabilities. They kept shouting for help and watched helplessly as the villagers ran away. Sarvanan was very brave and caught hold of his sister with the affected arm and held tightly on to a coconut tree with his good arm. He kept on holding till the waves receded and came out safely after the incident. Though they were not hurt all their belongings were washed away. The family has received same compensation as others i.e. rice, temporary shed, Rs. 4000/- and Rs. 1000/- once every three months. The elder son who is the only bread winner now cannot find any employment because the fishing activities have not resumed yet as the fishing owners have not been provided with fishing boats. Joseph Eye Hospital has supported the family by providing aids and appliances to Sarvanan and money for the girl's education. The family feels that the government does not have any schemes or plans for fishing labourers.

7. Pakriamma is a 25 year old girl from Pudukuppam with moderate polio. She is the second wife and has to care for five children of whom three children are from her husband's first marriage. The husband is a drug addict and does not contribute to the family income in any way. She has to work and take care of the children and the husband. One of the children died during tsunami. They received a compensation of Rs. 1 Lac for the death of the child and Rs. 8000/- for wooden boat. The husband is misutilising the compensation money and Pakriamma is struggling hard to make the ends meet. She counts days to receive the 30 Kg rice and Rs. 1000/- every three months that is being distributed by the government.

8. Karthik is a six year old boy whose father is Arumugham and mother is Marimuthu. He is deaf. There are nine members in the family. At the time when the waves hit, his mother had gone for selling the fish and father was about to leave for fishing. But every one is safe. Karthik was saved by his sister. The family has lost the only boat they had which costs about Rs. 65000/-

9. Jaish Kumar 9 years orthopedically handicapped boy studying in 3rd std. He used to live with his mother, brother and grand mother. He had lost his father three years ago. The killer waves took his mother and brother as well. Mother used to sell edibles on the seashore and that morning she had gone for usual business. Brother used to work as watchman watching the boats on the sea shore. Both of them were killed in

the surge. Jaish is left alone with his grandmother and there is no one to earn livelihood.

10. Karthik 13 yrs old, MD person, unable to walk independently. He has 2 elder brothers and 2 elder sisters. He lost his father and mother. While he was rescuing all the four family members, he got injured. The family has lost all the properties. Entire village Pattinacherry washed out. They have become shelter less. No food, water, no means of livelihood.

He lost his boat, which costs 1 Rs.lac Now he is the breadwinner of his family but he is unable to work and walk properly because of his injury.

11. Anjappan aged 35 yrs polio in right leg goes for fishing as labourer. He was earning Rs.50/- per day. Living in a hut on the seashore. 26th morning he was weaving fishnet close to the boat. Then killer waves hitted badly as a result he was sucked under the boat which was hitted by the waves. He became unconscious immediately. People pulled him out. As a result of this incident he has severe injury to his functional leg. Now doctor suggested not to walk for 4 months. Govt of Nagapattinam quickly warned fishermen not to enter sea for next 3-4 months. Anjappan lost all his property he is staying in temporary relief camp, dependent on food and shelter. He is very uncertain in his life. He has 2 children and wife. Luckily all of them are safe. But his 8-month-old child do not have natural anus. The stool is passing close to ribs. He had barrowed Rs.50000 for operation. All the money and property swept away. At present he is in dark.

Appendix 4: Handicap International's Work in Indonesia

Tsunami in South East Asia: Handicap International's work in Indonesia

Numerous humanitarian aid agencies are working in the areas affected by the tsunami in Indonesia. Handicap International's work and presence there follows a simple logic of:

- identifying the needs in our areas of expertise
- bringing relevant and long-term support
- working in close link with the local authorities and local relevant organisations. We do not try to replace them but instead aim at building their capacities for the future.
- not repeating what other agencies already do

According to Nicolas Heeren, Programme Director at Handicap International, "Handicap International must build bridges between Indonesian agencies and international organisations."

Our activities so far

Between the 18th January and the 31st March 2005, 2,105 physiotherapy sessions were provided and 471 patients were treated by Handicap International.

Handicap International opened a central office in Jakarta and three operational stations in Banda Aceh, Sigli and Meulaboh (Aceh province).

Our organisation currently has 11 expatriates and around 20 local staff working on various projects. Activities directly run by expatriates are progressively being replaced by support to local existing organisations, providing further training when necessary. Like in Sri Lanka, our emergency work with tsunami survivors is now moving towards actions in favour of disabled people in general.

Important needs - in link with our areas of expertise - have been identified, needs due to the tsunami but also needs existing before the natural catastrophe. In 2005, an evaluation of the needs in other parts of the country will be organised.

Our various projects in Indonesia cover:

- **Support to health structures** (emergency and medium term activities)
- **Capacity building in rehabilitation** (medium to long term activities)
- **Support to displaced people and disabled people** (emergency and medium term activities)
- **Disabled people and the rebuilding process** (medium to long term activities)

The risks are still important

Handicap International's activities in Indonesia are closely linked with the political situation of the country and the risk of further natural catastrophes. The position of Indonesian authorities vis-à-vis international aid is still not really clear. A deadline

given for 26th March, which later changed to end of April, should have marked the end of the emergency phase, meaning that NGOs not recognised by the authorities would have to leave the country. But criteria and procedures to be recognised have still not been really explained.

Disabled people and the rebuilding process (medium to long term activities)

Handicap International is aiming to:

- Ensure that disabled people are prioritized in the relief support and taken into account by other agencies
- Campaign for the rights of disabled people
- Promote the fact that new infrastructures should be made accessible

1) Our partnership with UN Habitat

The United Nations Human Settlements Programme, which coordinates the reconstruction of houses and public buildings in the Aceh province has chosen Handicap International as the reference organisation in terms of accessibility. UN Habitat will be building 697 houses in East Aceh. This means that Handicap International will be:

- Organising training sessions and providing technical support to organisations involved in the rebuilding process, so that new buildings will be accessible to disabled people
- Creating communication support to raise awareness of accessibility issues amongst construction engineers, builders and also individuals
- Advising on drawings and plans of private and public buildings
- Raising awareness on these issues amongst disabled people's organisations
- Training local architects

2) Inclusion of disabled people in the Indonesian society

In the near future, Handicap International will also:

- Start a national project to raise awareness on disabled people's rights.
- Set up activities at regional level to lobby, raise awareness and inform the population on disability and disability rights issues.
- Support local disabled people's organisations working to improve the social and economic inclusion of disabled people.

**Appendix 5:
Response of the European Commission to EDF/IDDC letter**



EUROPEAN COMMISSION
DIRECTORATE-GENERAL FOR HUMANITARIAN AID - ECHO

The Director-General

REÇU 31 JAN. 2005

Brussels,
ECHO-DG/AC/HK D(2005)

Réf. D. **833**
25. 01. 2005

Subject: Asia earthquake/Tsunami

Dear Mr. Vardakastanis and Mrs. Stubbs,

On behalf of the President of the European Commission and Commissioner Louis Michel I wish to thank you for your letters dated 4 January 2005.

Let me reassure you that the Commission shares the concerns of IDDC and EDF for the situation of disabled persons in Asia. In our response to the Tsunami disaster we must take into account the special needs of disabled persons, and ensure that relief assistance reaches these most vulnerable victims. In this respect the Commission has already committed funds to Save the Children's activities in Indonesia, and is currently considering funding decisions, which include other NGOs within IDDC. The Commission has, through its Directorate-General for Humanitarian Aid (ECHO), so far committed € 23 M to support the victims of this disaster. More detailed information on the response of the European Commission is available on our web-site <http://europa.eu.int/comm/echo/>.

I wish to thank you for your generous offer of expertise and cooperation in these matters.

Yours sincerely,

António CAVACO

Mr. Yannis Vardakastanis
President, European Disability Forum

Mrs. Sue Stubbs,
Coordinator,
International Disability and Development Consortium

39-41 Rue du Commerce
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Commission européenne, B-1049 Bruxelles / Europese Commissie, B-1049 Brussel - Belgium. Telephone: (32-2) 299 11 11.
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