Intellectual/Developmental Disabilities and Conflict – Advocacy of the forgotten

What are the experiences of persons with intellectual/developmental disabilities in violent conflict and post-conflict situations? – with a focus on humanitarian assistance

Brigitte Lea Rohwerder

Master of Arts in Post-War Recovery Studies

University of York

Post-War Reconstruction and Development Unit – Department of Politics

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Abstract:

"Too often invisible, too often forgotten and too often overlooked" (Guterres in WRC 2008: 1)

Introducing a social model of disability to post-war recovery studies, this dissertation examines and analyses the experiences of persons with intellectual/developmental disabilities who have been neglected in practice and academia, focusing on their interactions with humanitarian assistance. Such invisibility, combined with the disabling impact of society, their low priority, and the nature of their impairments, results in a disproportionate impact of conflict on persons with intellectual/developmental disabilities in conflict. They face increased risk of death and injury, both deliberately and as a consequence of their disabilities; have been left behind as others fled, starved, been abandoned by their carers, abused, faced problems accessing education, employment and health services, and have been ignored in the post-war reconstruction phase.

Drawing on a wide range of sources, including humanitarian workers, this dissertation examines these experiences and analyses how much consideration there has been of persons with intellectual/developmental disabilities in humanitarian assistance policy and practice. It identifies several key documents that have served to increase disability awareness and protection, yet illustrates the issues these face in meeting the needs of persons with disabilities. Translation into practice is also analyzed, looking at the attitudes which result in the lack of consideration of persons with intellectual/developmental disabilities. The dissertation then examines the potential for change that accompanies conflict, which can help create a more inclusive society. It examines the need for a transformation of attitudes in humanitarian organizations to improve the success of disability policy and the benefits of using a social model of disability. It suggests ways in which the vulnerability of persons with intellectual/developmental disabilities can be tackled so that persons with intellectual/developmental disabilities face the next crisis from a position of greater strength. Recognising the inherent equal worth and dignity of every human being, despite their differences, is important for the inclusion of persons with intellectual disabilities in society and humanitarian assistance.

Having for so long forgotten about the plight of persons with intellectual/developmental disabilities in conflict, it is important to finally start paying attention.

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Acknowledgements:

Author's Declaration

This work is being submitted in partial fulfilment of the requirements for the degree of MA in Post-war Recovery Studies at the University of York.

It is my own unaided work, except where otherwise stated, and has not previously been submitted for any degree or examination.

Signed

.... (Candidate)

Name: Brigitte Lea Rohwerder (Full Name)

University of York, Heslington

Date:

<u>Acronyms:</u>

ACTD	Agency for Technical Cooperation and Development
ADD	Action on Disability and Development
CBM	formerly Christian Blind Mission
DFID	Department for International Development
DPI	Disabled Peoples' International
DPO	Disabled Persons' Organisation
EDF	European Disability Forum
EENET	Enabling Education Network
EFA	Education for All
HI	Handicap International
IDDC	International Disability and Development Consortium
II	Inclusion International
INEE	Inter-Agency Network on Education in Emergencies
INGO	International Non-Governmental Organisations
JoDID	Journal of Disability and International Development
LCD	Leonard Cheshire Disability
LNFOD	Lesotho National Federation of Organisations of the Disabled
LSMHP	Lesotho Society of Mentally Handicapped Persons, Parents and Families
NGO	Non-Governmental Organisations
OCHA	Office for the Coordination of Humanitarian Affairs
RaDO	Rehabilitation and Development Organisation
SEU	Special Education Unit
UN	United Nations
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
UNESCO	United Nations Educational, Scientific and Cultural Organisation
UNHCR	United Nations High Commissioner for Refugees
UNICEF	United Nations Children's Fund
WHO	World Health Organisation
WRC	Women's Refugee Commission

Title: *Intellectual/Developmental Disabilities and Conflict – Advocacy of the forgotten*

What are the experiences of persons with intellectual/developmental disabilities in violent conflict and post-conflict situations? – with a focus on humanitarian assistance

War affects everyone but in war and its aftermath "life favours 'those who have' – healthy, strong, smart, multi-skilled individuals, living in supportive families and with access to money and [connections]" (Closs 2003: 148). Those who lack this are the ones who tend to be the most negatively affected. One of the most vulnerable groups in the population are those with intellectual/developmental disabilities, who tend to be invisible and at the bottom of the list of already under-valued and low-priority people with disabilities.

Intellectual disability is defined as a condition of significantly below average cognitive functioning combined with limitations in adaptive behaviour (Grove et. al. 2010: 85), which by its nature puts people with intellectual/developmental disabilities at an "elevated risk of abuse" (Owen and Griffiths 2009: 16). Grove et al. (2010: 88) point out that people with intellectual/developmental disabilities are "generally more prone to abuse and maltreatment, whether psychological, physical, emotional or sexual" because of their "incapacity to protect or even to understand their own interests" (Koh and Gostin 2003: 3).

From the Nazi policy of "wild euthanasia" (Herr 2003: 117), to Sierra Leone where anecdotal evidence suggests that soldiers shot dead on the spot any disabled persons they came across (Harris 2003: 21), to those maimed and injured during conflict or as a long-term result of it in the case of victims of dioxin poisoning in Vietnam (Tho 2010: 225), disabled people have felt the "negative impact of the crisis more keenly than other citizens" (Harris 2003: 20); while war has caused their numbers to rise. They face increased risk of death and injury, both deliberately and as a consequence of their disabilities; have been left behind as others fled, starved, been abandoned by their carers, abused, faced problems accessing education, employment and health services, and have been ignored in the post-war reconstruction phase.

Disabled people make up 15% of the world's population (WHO 2011), and an unknown proportion of the population is affected as family and carers, yet, while there has been an increasing acknowledgement of the need to differentiate between the impacts of conflict on populations, there has been little research into the experiences and needs of people with disabilities. Persons with intellectual/developmental disabilities, despite their greater vulnerability compared to the rest of the population, find themselves one of the

lowest priorities of all, due to the ignorance or prejudices of wider society. The problem this dissertation wishes to address is: how then do people with intellectual/developmental disabilities cope in conflict and post-conflict situations and how can their value be recognised so that their needs are also considered in conflict and post-conflict times?

As a result, the key question the dissertation asks is: What are the experiences of persons with intellectual/developmental disabilities in violent conflict and post-conflict situations? – with a focus on humanitarian assistance, in order to give voice to the experiences of people with intellectual/developmental disabilities and look at what protections exist for this at risk group as a result of who they are and the risks they face due to their position in society and their place in humanitarian assistance. A number of sub-questions will help to expand on this issue and attempt to draw out solutions to additional problems above those faced by all in conflict and post conflict contexts.

- How much consideration has there been of people with intellectual/developmental disabilities in humanitarian assistance policy and practice?
- How can their vulnerability be decreased?

My research will show that people with intellectual/developmental disabilities suffer from the impacts of conflict disproportionately to other sections of society. They are overlooked and their needs are neglected. Finding themselves low priority, they struggle to access services and have a voice that is paid attention to. Despite the existence of a number of enshrined rights and other international documents that provide a guiding principle for disability rights, there is still a very long way to go, as in the implementation stage their rights are not being met and the response to their needs is generally non-existent or inadequate. They and their carers strive to overcome the difficulties they face in society, caused not by their disabilities but more as a result of physical, attitudinal and institutional barriers, although some efforts have been made to address their needs and advocate for their rights by international organisations and local disabled person's organisations (DPOs).

The lack of attention towards disability in conflict exists in both academia and amongst those working in the field. Despite interest amongst some organisations, which has resulted in the creation of disability policies, this has been acknowledged to be on a more *ad hoc* basis, with much more needing to be done (Hastie 1997: 27). This dissertation goes some way towards addressing the deficit of attention in theory and practice to the experiences, needs, and rights of people with intellectual/developmental disabilities in conflict and post-conflict contexts. It is important that this deficit is overcome so that the equal rights of all human beings are recognised and ensured and that the most vulnerable do

not suffer needlessly due to the impact of war and so that the post-war reconstruction phase can result in positive change and equality for all members of society; especially persons with intellectual/developmental disabilities so that they come out of the shadows of neglect and inattention that leave them more at risk in situations of crisis.

Using a social model of disability, the dissertation will examine the experiences of people with intellectual/developmental disabilities in conflict and post-conflict situations and how these experiences arise out of the way in which they and disability are viewed by society and the actors they interact with, including international organisations engaged in relief and reconstruction work.

This dissertation takes as its area of study the experiences of people with intellectual/developmental disabilities in a variety of contexts rather than doing a specific country focus. This is due in part to the lack of opportunity to conduct first-hand fieldwork with people with intellectual/developmental disabilities but also to illustrate that this is not a country specific problem but one which faces what Tim Wainwright of Action on Disability and Development (ADD) International describes as the "world's largest minority" (Mc Veigh 9.6.2011) in all countries where conflict and crisis occur.

Before going on to outline the structure of the dissertation, I will make a quick note on the use of language. Negative phraseology can be damaging and many of the words used to describe people with intellectual/developmental disabilities previously are now considered offensive and disrespectful. What is considered appropriate terminology continues to evolve. As international consensus seems to be leaning towards the use of intellectual/developmental disabilities I will use this term[1]. However, I will use both disabled people (common in the UK) and people/persons with disabilities (common in the USA) as they have both frequently appeared in my research.

Chapter 1 outlines the methodology and the social model used as a framework. Chapter 2 will be a literature review looking at the confluence of disability and post-conflict studies and the gaps which exist, especially when it comes to the representation of persons with intellectual/developmental disabilities. Chapter 3 looks at the experiences of persons with disabilities pre-, during, and post-conflict, and flags up the differences amongst persons with disabilities and the forgotten element of families. Chapter 4 looks at how much consideration there is of disability and especially intellectual/developmental disability in

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[1] References to intellectual/developmental disability in the literature continue to use terms such as mental disability, mentally handicapped, mentally retarded, cognitive disability or refers to individual types such as autism.

policies and guidelines used by humanitarian organisations, while Chapter 5 takes this a step further to examine implementation and practice, considering why persons with intellectual/developmental disabilities are overlooked in humanitarian assistance. Chapter 6 addresses the potential for change that conflict brings and what might be done to grasp the opportunity to create a more inclusive society that reduces the vulnerabilities of persons with disabilities. The conclusion reflects on the problem this dissertation addressed and on the main research question, as well as suggesting areas for further research.

While the "vulnerability of the population as a whole is increased in a crisis; … given the scarcity of resources, people's needs have to be prioritised. Those whose value is not recognised are given lower priority" (Harris 2003: 22). People with intellectual/developmental disabilities are amongst the most at risk sections of society, due to the societal barriers they face and the lack of value that is attributed to them. Disabling barriers and negative attitudes increases their vulnerability in conflict and the post-conflict reconstruction period. However, "war creates chaos but the destruction of old systems potentially clears the way for change" (Closs 2003: 151) and further advocacy and the implementation of rights, as well as the adoption of a social model of disability, could lead to an improvement of the situation that people with intellectual/developmental disabilities and disabled people in general face during and after conflict.

Methodology:

Disability in conflict and post-conflict contexts is an extremely under researched area which made it an important yet challenging topic to research, especially due to the lack of opportunity to conduct first-hand research in a conflict or post-conflict context. However, these challenges can go some way to being overcome through the use of triangulation and a diverse range of sources, including a combination of fieldwork into disability advocacy, and interviews with field practitioners working with disabled people in conflict and post-conflict contexts, as well as case studies found in previously published work relating to the topic of disabilities in conflict.

Research Process:

My interest in disability and conflict arose when I became curious about the linkages between my upbringing in a life-sharing community for people with intellectual/developmental disabilities, and my studies of post-war recovery studies. Apart from landmine survivors there was little mention of persons with disabilities in conflict during my studies and thus I was inspired to investigate further. My initial searches for information produced very little substantial information but I was not prepared to accept that persons with disabilities experiences of violent conflict were so similar to the rest of the population as to warrant no extra attention and resolved to investigate further. That led me to discover that what information there was on persons with disabilities in conflict tended to focus on those with physical disabilities, with people with intellectual/developmental disabilities appearing to be largely invisible in the literature. Yet my personal experience made me recognise that there were differences between people with disabilities and impressed on me of the importance of the need to diversify the literature of persons with disabilities in conflict so that it included the experiences of persons with intellectual/developmental disabilities. Their invisibility in the literature and in the practice of humanitarian assistance, combined with their vulnerability due to the nature of their impairments and the disabling impact of society, made the question of what are the experiences of people with intellectual/developmental disabilities of violent conflict and post-conflict situations seem particularly pertinent.

Tools used:

The majority of research conducted was qualitative, as in the circumstances, and for this initial study, it was felt that it was more suitable because it would provide rich and in-depth

information, better reflecting people's experiences. An additional reason for the use of qualitative rather than quantitative data is the lack of statistics and data on persons with disability in general.

I undertook some fieldwork in Lesotho, which, while not a post-conflict country, faces many similar problems and attitudes to those found in conflict affected countries as severe tension exists in society between people with disabilities and the wider population, with historical beliefs about people with disabilities fuelling discrimination, stigma and in some cases neglect. Resultantly, it was a good context in which to study rights advocacy by and for people with disabilities. However, the context I was really interested in was that which has largely been ignored in disability studies, conflict and post-conflict contexts, which resulted in the search for data relevant to this area through other means.

The inability to conduct first-hand research was advantageous in that it allowed me to have a broad focus for research that was not limited to one context. While no country is the same and the context-specificity of each environment should be recognised, there are many similarities in the experiences of people with intellectual/developmental disabilities in conflict and post-conflict situations that can be effectively drawn out from a multiple-context focus. The diversity of contexts represented is an important point as it reflects the diversity of experience that exists amongst persons with disabilities and highlights the need for considered responses that acknowledge the individual as well as the collective experience.

Semi-structured interviews: Face-to-face interviews were conducted in Lesotho with the heads of three DPOs relating to people with intellectual/developmental disabilities as well as two representatives from the Special Education Unit (SEU) of the Ministry of Education. More were carried out via telephone in the UK with representatives from Save the Children and Oxfam, as well as an academic working on disability issues.

These interviews provided a lot of useful information from people with an overview of the topic and were flexible enough to adapt to the new information I was receiving, helping direct my research towards the pertinent issues. However, the lack of prior information and knowledge of the situation on the ground can mean the focus of the questioning may not be drawing out the most important information, which is why flexibility is important. It would have been useful to be able to conduct interviews with people with intellectual/developmental disabilities themselves but I was unfortunately unable to get in contact with anyone. This was an issue of access and language.

E-mail correspondence: was conducted with a large number of people who worked for international humanitarian organisations, disability specialist NGOs and DPOs, including, but not limited to: UNICEF, Women's Refugee Council (WRC), Action on Disability and Development (ADD), Oxfam, CBM, Leonard Cheshire Disability (LCD), Handicap International (HI), Disabled Peoples' International (DPI), Atlas Alliansen, Eurasia Association and Foundation, Save the Children, Deaf Africa Fund, World Vision, Department for International Development (DFID), as well as a number of academics.

This correspondence provided lots of interesting and useful information, as well as anecdotal evidence from a wide variety of sources who felt they lacked the information to contribute more than what they shared in their emails. Although the lack of a set list of questions meant that the information I was getting was not always in depth it was still very useful to gain people's impressions, as both what they did and did not know were relevant indicators, for example, of the amount of consideration there was of people with intellectual/developmental disabilities in humanitarian assistance.

Literature review: the inability to conduct first-hand research on disability in conflict and post-conflict settings was partly overcome through a review of relevant literature which was able to provide a number of examples of field research conducted into the topic. Also reviewed were policy documents and guidelines, news articles and academic articles that were concerned with humanitarian action, disability issues and the linkage between the two.

The most challenging aspect of the literature review was the difficulties faced in finding relevant literature. Many important and relevant articles could only be found after arduous searches, aided by rephrasing the initial search terms and following up bibliographies. The literature review provided both a broad overview of the issues and specific cases relevant to people with intellectual/developmental disabilities in violent conflict and post-conflict settings.

Quantitative data comes from a survey carried out of the number of times intellectual/developmental disability (or any of the other terms referring to it) were mentioned, in order to gain an impression of how much attention was being paid to this neglected group. As the search was focused on people with intellectual/developmental disabilities, there may be a disproportionate amount of references to them than generally would be found in the literature on disability and conflict.

Conferences and seminars: provided the opportunity to listen to speeches and discussions, as well as offering the opportunity for unstructured interviews with speakers and attendees. The Royal Society of Medicine hosted a talk entitled "Mainstreaming disability into humanitarian assistance: how far have we come?"[2], while I also attended the Manchester Metropolitan University conference on "Disability and the Majority World"[3].

While the latter was not always that relevant to my specific topic it provided a good impression of the current debates in disability studies, while the former was very relevant and gave me the opportunity to ask about people with intellectual/developmental disabilities in humanitarian assistance.

Unstructured interviews: valuable information was also gained through general conversations with people, occurring on an *ad hoc* basis and with no set structure. Such interviews occurred at a number of different conferences on disability, as well as chance meetings with people working in academia and the humanitarian sector.

While a lot of the information gathered might be irrelevant or off-topic, it was a useful way of finding out what people thought about the topic more generally.

Triangulation was achieved through the use of the wide variety of methods and sources, producing interesting data and serving to either reinforce the findings or illustrate contradictions and weaknesses, and cover any gaps a single approach would have. However there are also drawbacks to the focus on qualitative data, primarily the fact that a lot depends on the subjective interpretation of the researcher. This can be countered by being aware of and understanding one's own subjectivity and employing reflexivity.

Framework:

The main framework used is the social model of disability, which is tied into a human rights framework. From a human rights perspective "the intellectually disabled rank amongst the most vulnerable and at risk populations" (Koh and Gostin 2003: 2), a situation worsened by the chaos of war. The social model of disability offers a new approach for Post-War Recovery Studies, as well as linking it to the field of disability studies and providing an explanation, perhaps, of why there has been relatively little interest in disability issues in this field, due possibly to the attitudinal barriers outlined below.

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[2] Attended 24.6.11
[3] Attended 7-8.7.11

The social model of disability differs from both the medical and charitable model of disability by seeing the disability lying not with the individual but with the physical, institutional and attitudinal barriers placed on them by society. The medical model locates the problem in the disabled individual themselves, with people with disabilities seen as passive patients to be fixed (Harris 2003: 15). The charitable model views disabled people as victims of impairment who are to be pitied and cared for and who should be grateful for the charity and services they receive (Harris 2003: 16). Such models deny the ability of the disabled individuals and do not recognise the societal barriers that hold them back from reaching their full potential.

The social model sees the problem lying in the way in which society has organised itself with little consideration of people who have impairments, thus serving to exclude them from participation in mainstream societal activities (Harris 2003: 17). Disabled people are faced with physical barriers (exclusion from the built environment); institutional barriers (systematic exclusion or neglect in social, legal, educational, religious, and political institutions) and attitudinal barriers (negative valuations of disabled people by non-disabled people) that deny them equal rights and leave them vulnerable (Harris 2003: 17). The problem lies not in the individual or their impairment but in society's response to them and thus the problems faced by people with disabilities can only be solved by changes within society rather than the impaired individual (Harris 2003: 15-17). Society must be helped made accessible for disabled people, rather than forcing disabled people to adapt to it (Hastie 1997: 23). The social model also highlights that vulnerability is not the same as helplessness and it encourages people with disabilities to know their rights and advocate for them and other needs that they have.

The needs of people with disabilities are basically the same as those of people without disabilities and the claims they make for them and their rights are very similar to those made by other civil-rights movements (Harris 2003: 17-18, 28). A rights-based approach recognises that disabled people are also entitled to the same rights as everyone else even if their entitlements are frequently denied to them, especially in times of conflict and post-conflict when their rights are considered to be low priority. It must also be recognised that "the inequitable effects of crisis – the fact that the impacts are harsher for marginalised groups than for other groups – are also primarily a matter of human rights" (Harris 2003: 23), therefore reinforcing the importance of taking a human rights approach. However the human rights movement has tended not to focus much on the rights of people with

intellectual/developmental disabilities and ensuring that they enjoy the rights they have remains a challenge (Renteln 2003: 60; Lecomte and Mercier 2009: 67).

Challenges and ethical issues:

Access: the lack of opportunity to conduct first-hand research with persons with intellectual/developmental disabilities who have experienced conflict presented a data collection challenge. This was partly overcome by talking to as many people as possible with first-hand experience and trying to appeal for first-hand accounts through the DPI newsletter and various DPOs. It also ties into the ethical dilemma of representation and voice detailed below.

Language and terminology: the ability to speak other languages would have offered opportunities to interview more people in the field and people with intellectual/developmental disabilities in conflict and post-conflict situations. This was partly overcome by speaking to as many different people as possible from a range of different contexts. As persons with intellectual/developmental disabilities may have communication difficulties a questionnaire using simple to understand language was drawn up in consultation with people working with people with intellectual/developmental disabilities in the event of an opportunity for interviews arising[4].

In addition, there continues to be a debate about terminology. Misunderstandings arising out of this, such as the conflation of mental disabilities and mental health[5], may lead to confusion in the data. Therefore efforts were made to clarify terminology if confusion arose.

Biases: as well as my own, I have to be aware of the biases of my sources. The people interviewed were people already interested in disability issues and therefore it may perhaps appear that there is greater interest within these organisations than might actually be the case. This is illustrated by the lack of interest shown in the topic by a number of people working in the humanitarian field during personal conversations[6]. Talking to other people and reflexivity has helped me keep a perspective of the issues and made me aware of my own

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[4] See Appendix 1
[5] For example in email correspondence with DFID
[6] Carried out during the Advanced Course on Crisis, Conflict and Transitions – York 20-27.7.11

and others biases. However, biases can also be a valuable resource if used in a transparent manner.

Sampling: due to lack of access, time, language, up-to-date information and response levels, sampling was problematic. This was partially overcome by contacting as wide a number of people as possible and trying to follow up on non-responses. From my initial contacts and a review of the literature I was able to snowball my sample to include other relevant sources.

Literature focus: there is very little literature on disabilities in general in conflict and post-conflict settings, let alone on persons with intellectual/developmental disabilities. Much of the literature combines natural emergencies with man-made crises but focuses more on the former to the informational detriment of the latter. While this poses a challenge it also forms part of my argument that not enough attention is being paid to disabilities in conflict.

Ethical issues:

Vulnerable populations: When studying devastated and vulnerable individuals and societies there is a particular danger of doing additional harm (Olujic in Barakat et al. 2002: 994). Persons with disabilities, especially those with intellectual/developmental disabilities are especially vulnerable and therefore research with them requires a careful consideration of the ethics and power dynamics involved (Kellet and Nind 2001). Care should be taken to ensure that the researcher does not exploit them, and to make sure that they are comfortable with the process. As my own research was not directly with persons with intellectual/developmental disabilities this was mitigated to a certain extent, although I am still using them indirectly and therefore I have attempted to use this dissertation to strengthen their voice. Given the opportunity to conduct research with persons with intellectual/developmental disabilities my experience of growing up in a life-sharing community with people with intellectual/developmental disabilities, and working extensively with them has helped prepare me to communicate sensitively with them, and respect their needs. I would make sure to communicate with those around them as well, as they are likely to have a good understanding of the situation, and enable me to handle the power balance responsibly.

Representation and voice: the biggest ethical challenge lies in the issue of representation and voice. The dissertation seeks to present the experiences of persons with intellectual/developmental disabilities yet it is not being written by someone with

intellectual/developmental disabilities. Nor unfortunately does it contain the voices of directly interviewed persons with intellectual/developmental disabilities. Therefore how can I truly represent their experiences? I cannot; but I can highlight the need to be aware of their experiences of conflict by bringing to attention what has been observed.

Attitudes of those close to persons with intellectual/developmental disabilities, and the communication difficulties they experience as a result of these attitudes and their impairments, means that there is a "tendency …for others to speak for or represent them" (Owen et.al 2009: 36) when in fact they are imposing their own view of the situation on a group of people who lack the voice to challenge this interpretation. I hope I have mitigated this. I do not claim to fully represent the experiences of persons with intellectual/developmental disabilities, I only wish to draw to attention to the sparse information available and therefore advocate for the need for greater voice for persons with intellectual/developmental disabilities. I hope that some awareness raising is better than the current invisibility of persons with intellectual/developmental disabilities and that if someone starts by looking at the issue, people will then realise the need to start listening to the people who really have something to say; persons with intellectual/developmental disabilities experiencing the effects of conflict.

The methodology used seeks to bring together post-war recovery studies with disability studies through the use of a social model framework to address the gaps in the respective areas when it comes to disability in conflict contexts. Despite the challenges, especially around representation and voice due to the lack of opportunity to conduct firsthand research with persons with intellectual/developmental disabilities, the tools used hope to overcome these issues through the use of triangulation, as well as arguing that the challenges are not limited to this work but are an issue for the field in general. Persons with intellectual/developmental disabilities are a largely invisible population and more research is needed to include them in mainstream research.

Context setting and literature review:

In order to examine the experiences of persons with intellectual/developmental disabilities in violent conflict situations it is useful to establish the context within which this dissertation is being written in relation to the literature on persons with intellectual/developmental disabilities in conflict. This chapter outlines the context of the rights of persons with disabilities and the new United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), before going on to explore the emerging topic of disability in conflict and emergency situations and the key texts in this area. It will outline the gaps which exist, especially in relation to intellectual/developmental disabilities in conflict and situate this dissertation as an attempt to address this gap.

The struggle for rights – the right to life:

Historically the protection for persons with disabilities has been weak, with persons with intellectual/developmental disabilities "still rank[ing] among the most vulnerable segments of all society" (Robinson 2003: v). The Universal Declaration on Human Rights in 1948 contains no specific mention of disability for example (Endicott 2009: 11). Persons with intellectual/developmental disabilities have tended to have their human rights concerns overshadowed by protections for other disabilities, especially physical (Herr 2003: 118, Renteln 2003: 60), despite the fact that they continue to endure abuses of their rights, including their right to life from conception onwards (Watson and Griffiths 2009). Koh and Gostin (2003: 2) explain that from a human rights perspective "the intellectually disabled rank among the world's most vulnerable and at-risk populations both because they are different and because their disability renders them less able either to assert their rights or to protect themselves from blatant discrimination". Owen et. al. (2009: 35) argue that "[f]ear and threat, fed by ignorance, economic need and fluctuating social values have been the building blocks of barriers to human rights faced by people with disabilities".

Thus it is possible to see the background from which many of the issues examined in this dissertation emerge. The attitudes that place barriers in the path of the development of human rights for persons with disabilities are the similar to those that lead to stigma and discrimination, which in an "emergency setting is life-threatening" (Sparrow et. al. 2007: 13). These attitudes have resulted in weaker protections and value being placed on the lives of persons with intellectual/developmental disabilities, which combined with the nature of their impairments, leaves them additionally vulnerable, yet neglected, in humanitarian emergencies.

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD):

However, chiefly as a result of advocacy, progress has been made, and in recognition of the need for a human rights framework to protect the rights of persons with disabilities the UNCRPD was drafted in 2006. The UNCRPD is intended as a human rights instrument with an explicit social development dimension (Phillips et. al. 2010: 23), as it places a "duty on the Member State to combat negative stereotypes and prejudices against persons with disabilities" which have resulted in a disabling society (Lecomte and Mercier 2009: 65). While ultimately, it should help to improve the societal position of persons with disabilities, which should help to decrease their vulnerability in crisis situations, in the short term Article 11, which refers to disability in situations of risk and humanitarian emergencies, is where disability, conflict and humanitarian assistance meet by "raising disability issues in a humanitarian context"[7].

Article 11 states that "States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters" (UNCRPD 2006). When combined with the rest of the document Article 11 is a "powerful tool to ensure that people with disabilities are included in all aspects of humanitarian response and displacement, from recovery to rebuilding and resettlement" (Phillips et. al. 2010: 23). However, it is not clear what measures should be taken, while the existence of laws does not guarantee protection.

In recognizing the need for special protection of persons with disabilities in situations of armed conflict, the UNCRPD should be considered by those engaged in researching or working in such situations. Thus far, however, disability and conflict have had scant attention paid to them in both Disability and Conflict Studies.

The confluence of Disability and Post-War Studies:

Despite Disability Studies beginning to engage with development, especially as a result of the links between disability and poverty, this engagement has not stretched to the same level of interest in disability in conflict or crisis situations, with the exception perhaps, of the work of Maria Kett and colleagues.

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[7] Talk by Maria Kett at the Royal Society of Medicine 24.6.11

On the other hand, Post-war Recovery and related studies have also failed to engage with disability in conflict. The increased interest in vulnerable groups in humanitarian assistance has begun an engagement with issues around disability in conflict. With the focus on women and children, there has been an acknowledgement that there are elements of the population in need requiring additional consideration due to the discrimination and marginalisation they face in society, which means "the elderly, women and girls, minority groups and people with disabilities – can become the most vulnerable in a time of crisis" (Niskala 2007: 9). Yet, Couldrey and Herson (2010: 2) point out that it is "not (yet) common practice … to include people with disabilities among those who are considered as particularly vulnerable in disasters and displacement and who therefore require targeted response". Additionally, this approach is not without its own problems; if vulnerability is the only characteristic associated with persons with disability it can lose sight of their abilities and potential. Therefore it is important to look at vulnerability through the framework of a social model of disability. Additional encouragement has resulted from the emerging idea of rights-based assistance (Kett 2010: 343).

There is then, a slight confluence at which Disability and Post-war Studies meet and it is here that my dissertation situates itself and argues for the need for greater convergence between the two areas so that persons with disabilities, especially those with intellectual/developmental disabilities, no longer remain hidden in conflict situations.

Key texts in Disability in Conflict and Emergencies:

There a number of key texts that engage with this confluence of Disability and Post-war Recovery Studies and consider disability in conflict and emergencies. These include the Oxfam published "Disability, Equality and Human Rights - A Training Manual for Development and Humanitarian Organisations" which argues that "Disability Equality must become part of the everyday reality of humanitarian … work", with existing ways of thinking and working needing to change as in any crisis "disabled people are likely to feel the negative impact of the crisis more keenly than other citizens" (Harris 2003: 2, 20). Harris examines the common excuses for the exclusion of disability in programmes, the need for Disability Equality, and how it can be implemented. There is recognition of the diverse impacts of conflict on people with different impairments and that "[p]eople with [intellectual/developmental disabilities] are…particularly exposed to risk" (Harris 2003: 21).

Another key text is another Oxfam published book, "disabled children in a society at war - A Casebook from Bosnia" (Hastie 1997) which also looks at the importance of

organisational attitudes for the success of programs engaging with disability and at the introduction of the social model of disability in a community at war.

The Forced Migration Review devoted its 35th issue to "Disability and Displacement" in recognition of the lack of inclusion of people with disabilities in programs targeted towards displaced persons despite their vulnerability requiring a targeted response.

The Women's Refugee Commission wrote a report in 2008 considering "Disabilities among refugees and conflict-affected populations" examining the invisibility of persons with disability in refugee populations, illustrating good practice and making recommendations where progress was required. It found that "[r]efugees with mental disabilities tended to be more "invisible" and "hidden" from public view than those with physical disabilities" (WRC 2008: 2).

Another important writer in this area, who has authored and co-authored many articles on disability in conflict and emergencies, is Maria Kett. These include "Disability in conflict and emergency situations: Focus on Tsunami-affected areas" (with Stubbs and Yeo 2005); "Disability and Disasters: towards an inclusive approach" (with Twigg 2007) and "Disability and Poverty in Post-conflict Countries" (2010). They examine the neglect of research into disability and disasters, and examine them using a social model analysis. Much of the focus has been on natural disasters rather than conflict and highlights the importance of including disability in humanitarian work and what the current state of mainstreaming disability in humanitarian assistance is. The focus is on disabilities in general.

The under-representation of intellectual/developmental disabilities:

There were however few mentions of persons with intellectual/developmental disabilities in the above texts and in the literature in general. In a survey of roughly 38 documents, 10 included no mention at all, while another 10 had only one mention, while out of the remaining documents, only 10 contained five or more mentions. Indeed, their neglect in practice in favour of those physically impaired during the conflict is echoed by the under-representation of persons with intellectual/developmental disabilities in the literature. Often there are just references to persons with disability in general, which while understandable, does not reflect the differences amongst persons with disabilities, or lip-service is paid to them, or no mention is made at all. While in other cases there was even confusion as to what was classified under intellectual/developmental disabilities, especially the conflation in a number of different cases of mental health and mental disabilities (WRC 2008: 8). There were only two documents directly addressing the experiences of persons with

intellectual/developmental disabilities in conflict, the Grove et al (2010) article "Intellectual Disability and War: Issues for Consideration" and a document published by the Kenya Association for the Intellectually Handicapped (2008), "Impact of Post-election Violence on Persons with Intellectual Disabilities and their families".

Grove et al highlight the paucity and inaccuracy of information on disability in conflict, especially in relation to intellectual/developmental disabilities and examines the effects of war on them. It provides an important introduction to the topic but unfortunately does not include fieldwork research. The report from Kenya, on the other hand provides first-hand evidence about the experiences of persons with intellectual disabilities and their families of the election violence but it is not an academic document so does not provide analysis. With only two documents examining conflict and intellectual/developmental disabilities there is clearly a need for more work that examines the experiences of persons with intellectual/developmental disabilities in conflict.

In conclusion, all in all disability is very much underrepresented in post-conflict studies, and more specifically, persons with intellectual/developmental disabilities are "more often than not, a completely hidden population"[8]. This gap in knowledge of the experiences of persons with intellectual/developmental disabilities has been recognised by many, with many correspondents commenting on the importance of my question[9] and the Chair's Summary of the recent conference on "Disability in Conflicts and Emergencies" noting that one of the recommendations emerging was the need to address the "gap in research and knowledge about the needs of persons with intellectual disabilities in emergencies and situations of conflict" (Sæbønes 2011: 3). This dissertation attempts to address this gap and draw attention to the shared and individual experiences and needs of persons with intellectual/developmental disabilities in conflict and humanitarian assistance, which has thus far been largely forgotten in narratives of conflict and assistance.

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[8] Interview with Charlotte Balfour-Poole Save the Children UK 17.6.11
[9] Valerie Scherrer, Rebecca Shea, Joan McGregor, Eric Emerson, David Hulme, Peter Coleridge, Washington, Frances Stewart, Elin Fjestad, David Felce

Experiencing conflict:

Persons with disabilities, especially those with intellectual/developmental disabilities, tend to be low priority even in non-conflict situations. This low prioritisation is due in part to the disabling impact of society and results in them being more vulnerable in violent conflict and its aftermath. The effects of conflict have a compounding and worsening impact on their already vulnerable position in society and damage their support networks. This chapter goes on to outline the experiences of persons with disabilities, looking where possible at the specific experiences of persons with intellectual disabilities and their families during the various stages of conflict, touching briefly on the post-conflict stage too, and highlights the importance of addressing their needs due to the nature of their experiences, as well as the paucity of available data.

Low Priority – the situation prior to conflict:

In many contexts, the disabling impact of society, with its physical, institutional and attitudinal barriers, means that "[d]isablity is very low on most government agendas" and considered a low priority for attention and funds (Swain et. al. 2005: 166). The lack of value placed on them is often a result of ignorance or prejudice as to what they have to offer to wider society and results in attitudes which hold persons with disabilities back and prevent spending on measures that would remove some of the barriers faced. It leads to unemployment, lack of education, poverty, risk of health problems and abuse. This has resulted in a situation in which persons with disabilities are marginalised and vulnerable, with persons with intellectual/developmental disabilities being one of the "most marginalised and vulnerable groups" of all (eds. JoDID 2011: 3), and facing a "significantly higher risk of poverty and social exclusion than other groups" (Letavayova 2011: 18). They lack the same levels of access to basic services as other members of the population and often do not receive the required levels of support to live a fulfilled life. This has a knock-on effect on their family who often have to bear the brunt of providing support which can leave them impoverished and in some cases marginalised, as a result of negative social attitudes towards their family members with disabilities (WRC 2008: 12). Mothers are often blamed and abandoned if they give birth to children with intellectual/developmental disabilities (WRC 2008: 12). It is important to remember that disability can negatively affect not only those with disabilities but their families and carers as well.

Letavayova (2011: 18) argues that the needs of people with intellectual/developmental disabilities are neglected by the community and public authorities

as a result of the combination of extreme poverty and deep-rooted social stigma caused by prejudice, superstitions and strong negative attitudes towards people with intellectual/developmental disabilities and that this often leads to the exclusion of whole families from the community. Such exclusion leaves persons with intellectual/developmental disabilities facing greater problems in dealing with the consequences of the crisis as they start from a position of less resources and weaker support structures; their vulnerability increasing in the shocks and crises that come with conflict and the destruction of existing support networks.

Direct targets – (intellectual) disabilities in violent conflict:

Persons with disabilities have been direct targets during violent conflict (Gulu Disabled Persons Union 2010: 18). Perhaps the most notorious and large-scale is the case of the "wild euthanasia" (Herr 2003: 117) of persons with disability in Nazi Germany, where an estimated 90 000 to 270 000 were killed (Owen et al. 2009: 28; Herr 2003: 117). Inspired by ideas of social Darwinism, persons with disabilities were deemed not fit to live as their lives were held to be of less value and "not worth living" as they were "useless eaters" (Herr 2003: 118).

Similar attitudes persist in recent times, with anecdotal evidence from Sierra Leone suggesting that persons with disabilities were deliberately shot dead by soldiers to "put them out of their suffering" (Harris 2003: 21). In Rwanda, although the motives are not clear, almost all the 700 patients "with learning difficulties and mental health problems in Rwanda's psychiatric hospital" were killed (Light 2003).

Watson and Griffith (2009: 78) argue that persons with intellectual disabilities continue to have a low value placed on their right to life, resulting in euthanasia and murder, through actions such as abortion, withholding of medical procedures, drug overdoses and "mercy" killings. If the right to life of persons with intellectual disability is not considered of equal worth in peace then it is unlikely that it will be valued or protected in situations of violent conflict. For instance, it has been reported that Amar Ahmed Mohamed, a 19 year old Iraqi with Down's syndrome, was befriended by a group of men who strapped him with explosives and sent him to a voting station where he was detonated (Watson and Griffith 2009: 91), displaying a blatant disregard for his right to life, using and discarding it for their own violent ends. There are other unconfirmed reports of a wider policy of using people with Down's syndrome in Iraq as suicide bombers (Quarmby 2008).

Direct impacts of violent conflict:

More common however, than deliberate targeting, is death or injury through the direct impact of the violence on the population. Such injuries may lead to impairments and subsequent disability, with humanitarian crises being recognised as a contributor to disability (WHO 2011: 34). Chemical warfare, such as the use of Agent Orange in Vietnam, has also resulted in increased instances of disability, including intellectual/developmental impairments. Mobility challenges and communication problems may result in persons with prior disabilities not knowing about the risks and finding it harder to flee violence, therefore increasing the likelihood of their being killed or injured (Masakhwe 2004, Hastie 1997: 19).

Persons with intellectual disabilities may be disproportionately at risk of death and injury in violent conflict situations. Many continue to be cared for by their families or in institutions and the impact of conflict may damage their support networks and leave them more susceptible to risk (Barriga et al 2010: 6). For example, persons with disability in the former Yugoslavia living in care homes were abandoned by the staff unable to evacuate them quickly as the front approached [10]. Perhaps the greatest risks to persons with intellectual/developmental disabilities come as a result of them not understanding what is occurring or their difficulties in making themselves understood, especially as their disabilities are not necessarily visible. For example parents of children with intellectual disabilities in Kenya during the political violence in 2008 had to unwillingly confine their children indoors as they "didn't understand what was going on and always wanted to go where the sounds of gunshots were coming from" (Burugu (ed.) 2008: 7). When combined with ignorance as to the nature of their impairments from those with the power, this can lead to their deaths, as occurred in Israel where people with intellectual disabilities were shot dead because they did not understand what was occurring and thus did not obey the soldier's orders (Grove et al. 2010: 89), or in Kenya, where a man with Down's syndrome was stoned to death when he was unable to express himself while being interrogated (Burugu (ed.) 2008: 6). Difficulties in understanding the situation can make it even more traumatic[11].

Indirect impacts of violent conflict:

Violent conflict also disrupts and destroys services and daily life, which can lead to increased instances of impairments and disability, as well as causing deterioration in the quality of life of those disabled prior to the conflict. Disruption to health services and access

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[10] Talk by Major General Michael von Bertele 24.6.11
[11] Personal correspondence with Doreen Woodford

to food can lead to complications that result in disabilities, including intellectual/developmental, especially for children (Miles and Medi 1994: 290).

Disruption or destruction to basic services means that persons with disabilities and their families may face even greater problems accessing services, if for example they are further away or in unfamiliar places, which can lead to starvation. Where the nature of their impairments requires medical attention, the impact of violent conflict on health services can mean that these medical needs are not met and their condition deteriorates. Rehabilitation services that might be in place can also be disrupted by the conflict. Disruption to school services mean that those who were able to attend are left trapped in their homes more than they were before (Burugu (ed.) 2008: 5). The indirect impacts of violent conflict tend to lead to increased isolation of persons with disabilities.

Additionally, the indirect impacts of conflict mean that a great strain is put on the daily lives of people and the basic services provided by the state, which is combined with a period of limited resources as they are diverted to the conflict. In such instances prioritization once again occurs and the weak and those without voice tend to lose out, despite an increase in disabled people. Unless there is a change in attitudes and advocacy, persons with disabilities, especially with intellectual/developmental disabilities, who are not valued before the conflict, tend to be amongst those who lose out as they are perceived as an even greater burden in conflict (Harknett 2002: 4).

Flight and refuge:

When the violence of the conflict becomes too great or the disruption to daily life unbearable, people may flee. For families with disabled members this may sometimes lead to difficult decisions to leave them behind due to the difficulties in moving them or complex decisions about which children are most likely to survive, or in some cases what the family needs more. This lead to a father to chose to take the family's cow rather than their disabled daughter (Harknett 2002: 5.) and is "frequently the case for people with [intellectual/developmental disabilities]" (Harris 2003: 21). What happens to these persons with disabilities who have been left behind? Unfortunately no one really knows because humanitarian relief efforts are geared towards providing aid in refugee/IDP camps far from those left behind. However, a Human Rights Watch report from Uganda suggests that "those who could not [flee] often faced violence" (Barriga et. al. 2010: 24).

However many families go to great lengths to flee with their disabled family members (Pinnock and Hodgkin 2010: 34). They face greater protection risks as their flight tends to take on average almost twice as long (Kett and Trani 2010: 12), leaving them more exposed to the risk of being attacked, murdered and sexually assaulted along the way. During flight assistive aids may be lost or left behind, restricting the independence of persons with disability (Shiviji 2010: 5).

Upon arrival in the camps, persons with disabilities and their families are at risk of discrimination, stigmatization, harassment, neglect, exclusion, isolation, marginalization, and increased dependency, as well as facing problems accessing services (Panatzopoules 2008; Harris 2003: 21, Adbi and Matthews 2009). Often they are not registered, not included, forgotten and ignored, resulting in them becoming hidden and neglected in the refugee population, with persons with intellectual/developmental disabilities being most invisible and neglected of all (WRC 2009: 3; WRC 2008: 2). For example, at the recent conference on 'Disability in Conflicts and Emergencies' an urgent request for information about mental health services for persons with intellectual disabilities was met with silence[12]. The design of camps and the way in which people with disabilities are dealt with can heighten their disability and their potential is rarely recognised (Shivji 2010: 4, Reilly 2010: 8). Reports from Nepal also suggest protection issues for women with intellectual/developmental disabilities as they are especially affected by trafficking (WRC 2008: 33). There are of course instances where they may actually be able to access better services than they were able to in their places of origin, for example inclusive education has been pretty successful in refugee camps (WRC 2008, Wallis 2002: 4).

Post-conflict – recovery and reconstruction:

The end of the conflict brings with it its own problems and opportunities for persons with disabilities. For instance, relocation to a new neighbourhood raises fresh fears of stigmatization and discrimination (Burugu (ed.) 2008: 5), while persons with disabilities who have made it to refugee camps are often the last to leave because the provisions do not exist for their return and resettlement (Barriga et al 2010: 26). This includes lack of services and assistance in rebuilding homes. Additionally, in some cases, they are abandoned in the camps by their relatives (Eriku 2009, Sarr and Dube 2010: 7).

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[12] Personal correspondence with Valerie Scherrer CBM and Sylvie Cordier ADD

Unless changes are made and barriers eliminated, society remains disabling. In the recovery stage, support can decrease as, for example, "[o]verwhelmed by emergency issues, the Iraqi government has relegated [people with disabilities] to a low priority" (ATCD et. al. 2010: 15). Unless there is increased awareness through advocacy, awareness raising, and pressure from civil society, international NGOs, and donors for change and greater inclusiveness, it is unlikely that they will be considered. A common way that disability issues become prioritized post-conflict is through attention to injured war veterans percieved as heroes, as in Palestine (Canawati 2010: 1), but not so much in Liberia, where persons with disabilities actually faced increased discrimination because people associated disability with ex-combatants (Kett and Twigg 2007: 96). While this may bring disability to prominence, it can mean the focus is solely on the disabilities of veterans[13]. People who were born disabled or were disabled prior to the conflict are still seen in a negative light and persons with intellectual/developmental disabilities remain the lowest priority[14]. Disabled veterans DPOs may distance themselves from people who were disabled prior to the war as they are still perceived in a negative light[15] (Closs 2003: 159). It is not only veterans who may receive more understanding but people who have become disabled by the war in general (Moreira 2011: 101). For example, after the war in Mozambique there was greater understanding for children disabled by the war than those disabled prior to it, who were still not really accepted[16]. As people with intellectual/developmental disabilities tend to be disabled prior to conflict, they do not necessarily face greater acceptance in the post-conflict context unless there are changes to the attitude towards persons with disabilities in general and not just to the war disabled.

Box 1: Disabled Persons Organisations (DPOs):
DPOs offer persons with disabilities support and the opportunity to raise awareness and advocate for their rights. They can be either mixed or single disability and offer the opportunity to people with disabilities to realise their own rights and potential, which is especially important if they have previously internalised the negative attitudes that persist around disability (Harris 2003: 17). Where they exist prior to conflict they make it easier for humanitarian agencies to address disability issues as they can provide a source of information as to the needs and capacity of persons with disability in the area in times of crisis (Interview with Charlotte Balfour-Poole Save the Children UK 17.6.11). On the other hand the crisis itself may prompt the formation of DPOs so that persons with disabilities have greater opportunities to advocate for their needs when they are being overlooked in crisis situations.

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[13] Interview with Rachel Hastie Oxfam GB 11.7.11
[14] Interview with Charlotte Balfour-Poole Save the Children UK 17.6.11
[15] Interview with Rachel Hastie Oxfam GB 11.7.11
[16] Conversation with Susie Miles 24.6.11

> **Box 1: Disabled Persons Organisations (DPOs) cont.:**
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> However, DPOs do not necessarily represent the interests of all disabled persons. There are very few members with intellectual/developmental disabilities in DPOs (IDDC 2003). It is unfortunate but even amongst disabled persons themselves there exists a hierarchy of disability, as can been seen above with the case of some disabled veterans DPOs. Persons with intellectual/developmental disabilities are at the bottom of this hierarchy. Their needs and experiences of the conflict may be different from other persons with disabilities and therefore it is important to consider who it is exactly that the DPOs are representing when they are looked to for information in times of crisis so that persons with intellectual/developmental disabilities are not overlooked when disability is being considered.

A heterogeneous group – differences amongst persons with disabilities:

It is important to remember, then, that "persons with disabilities are a heterogeneous group of individuals, with different disabilities, genders and impairments and thus different needs and experiences" (eds. JofDID 2011:3). This is a very important point to remember because as well as the need to consider persons with disabilities as part of the general population with the same basic needs, there are a number of specific needs that need to be considered as part of meeting those basic needs (Scherrer and Mendis 2010: 40). Due to the disabling impact of society and the nature of their impairments, it may be more challenging for them to have their basic needs met. A solution for one person with a disability is not necessarily going to be appropriate for someone else with a different disability, due to other factors such as age, gender, ethnic group, social status and impairment.

Even amongst people classified with intellectual/developmental disabilities it is important to remember that there are differences within intellectual/developmental disabilities and spectrums of severity within these differences, which will impact on their individual needs.

Children, elderly persons and women with disabilities face greater problems than others amongst disabled people. Elderly people can be abandoned by their families as they are considered useless, children can be hidden and abused or left behind, women are at greater risk of sexual violence and abuse (Barriga et. al. 2010, Reilly 2010: 8, WRC 2008: 7). In addition the assistance programs may not be geared towards dealing with these more vulnerable elements. For example, a representative from Save the Children pointed out that there are no child focused disability NGOs working in the humanitarian sector[17]. But it is

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[17] Interview with Charlotte Balfour-Poole Save the Children UK 17.6.11

also important to remember that these differences affect all; if women are more vulnerable in the context then "disability becomes a compounding factor on top"[18].

Due to the different nature of their impairments and how they received them, persons with disabilities experience conflict in different ways. For instance disabled war veterans perceived of as heroes have a different experience of conflict than someone who is deaf; while persons who become physically disabled tend to be given greater attention and assistance than persons with intellectual/developmental disabilities (WRC 2008: 12). Persons with intellectual/developmental disabilities are at greater risk in situations of conflict (Bambi 2010: 15), yet they tend to be ignored and are one of the most invisible elements of the population due to the very factors that make them more vulnerable, such as issues with understanding the situation and making themselves understood, in a society that often is ignorant as to the nature of their impairments and negative towards them. Yet, as Frost (2003: viii) points out "invisibility can be lethal in situations of armed conflict". It is extremely important therefore that attention is paid to persons with intellectual/developmental disabilities and their individual and basic needs are addressed so that the vicious cycle of vulnerability and invisibility does not continue.

Families - the forgotten element

Additionally, considering the experiences of persons with disabilities is all the more important because of the impact on their families too (Reilly 2010: 8, Bambi 2010: 15). A soon to be published study by Oxfam and CARE of refugees fleeing the violence in Ivory Coast found that having a family member with a disability greatly increased the vulnerability of the whole family[19], while Adbi and Matthew's study (2009: 55) found that quality of life was better for families without a member who has a disability. This is important to remember, as the invisibility of disability causes some to dismiss it as an issue affecting too few people to merit special attention (Shivji 2010: 4). While there are many flaws with this assertion in and of itself, not least that disabled people are part of the general population and thus should have access to the same assistance as anyone else, when we consider all those involved in the lives of persons with disabilities it is clear that a more substantial proportion of the population is affected by disability issues than first apparent. Reducing the vulnerability of persons with disabilities will have the knock-on effect of reducing the vulnerability of their families.

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[18] Interview with Charlotte Balfour-Poole Save the Children UK 17.6.11
[19] Interview with Rachel Hastie Oxfam 11.7.11

In conclusion then, despite the information I have been able to find on the experiences of persons with intellectual/developmental disabilities in violent conflict and post-conflict situations, much of the evidence remains anecdotal and little of it focuses directly on their experiences. This lack of information means that there is a lack of realisation as to the needs of persons with disabilities in crisis situations, especially of persons with intellectual/developmental disabilities, as few can see or are interested in what is happening to them. There is however, increasing interest and efforts to gather data, such as the 2008 Women's Refugee Commission's study of refugees with disabilities. However there seems to be a tendency to lump the experiences of disabled people together, and while there are many similarities, this serves to hide important differences that should be acknowledged, especially when it comes to persons with intellectual/developmental disabilities. They are amongst the most vulnerable and invisible of all those affected by conflict. But this is not to say that they are helpless. For example, they contributed to the US war effort during the Second World War (Grove et. al 2010: 90-91). Given the opportunities which can emerge from the changes that conflict brings with it, the vulnerability and invisibility of persons with intellectual/developmental disabilities can be reduced and they can meet their full potential and be more resilient in the face of any new crisis.

Humanitarian assistance and people with intellectual/developmental disabilities - consideration in policy:

People with intellectual/developmental disabilities are part of the general population requiring assistance during crisis situations yet there is clearly a paucity of data on their experiences, which has a consequence for the way in which they are addressed by humanitarian actors (IDDC Task Group date unknown: 5). As a result this and the next chapter address how much consideration there is of people with intellectual/developmental disabilities in humanitarian assistance. This chapter shall go on to examine the policies and guidelines that exist for humanitarian actors to deal with disability in emergency situations and will look at how far attempts to mainstream disability in humanitarian assistance have come. The extent to which humanitarian policy recognises the diversity amongst persons with disabilities and the impact on families and carers will be explored throughout.

Humanitarian assistance:

In humanitarian emergencies, the needs of people with intellectual/developmental disabilities arise from the general conflict context and the impact this has on the lives of *all*, and include basic human needs such as security, food, water and shelter that are threatened by violent conflict and upheaval. Such basic needs are not immediately met with the ending of violent conflict and are challenged by the lack of resources and the priorities of the reconstruction process, as are other needs relating to quality of life, in a society that is striving to recover from violent conflict and return to "normal".

Furthermore the disabling impact of society may also affect the humanitarian assistance provided for persons with disabilities. Humanitarian assistance seeks to address the needs of people affected by natural disasters and man-made crises, including violent conflict and war. Its primary objective is to save lives, alleviate suffering and maintain human dignity. It seeks to address the needs of the general population in crisis situations. As part of the general population people with intellectual/developmental disabilities should theoretically have their needs addressed. Their additional needs, however, arising out of the disabling impact of society before, during and after violent conflict, as well as a result of the nature of their impairments that make them particularly vulnerable to the negative impacts of violent conflict, may not be met by humanitarian assistance if it fails to recognise this variance. There has however, been increasing recognition that there are certain vulnerable groups who need special attention in order for them to have equal access and opportunity to

benefit from humanitarian assistance in a challenging environment favouring the strong, including persons with disabilities.

Policies and Guidelines:

The increasing recognition of people with disabilities as a vulnerable group has lead to the inclusion of specific references of people with disabilities in a number of guidelines and policies relating to humanitarian action and to a reference to conflict and emergencies in the UN Convention on the Rights of Persons with Disabilities (2006). The acknowledgement that persons with disabilities have the same basic needs as others has lead to humanitarian organisations who serve the population in general to develop policies or guidelines on disability. For example Oxfam has published a training manual for development and humanitarian organisations entitled "Disability, Equality and Human Rights" that aimed to highlight the need to make Disability Equality an everyday reality of humanitarian and development work so that it will "lead to greater inclusion, equality, and rights for disabled people" (Harris 2003: 28). It acknowledges that "people with [intellectual/developmental disabilities] are known to be particularly exposed to risk" and that a lack of understanding of their needs leads to their needs being overlooked (Harris 2003: 21-22) and so highlights the diverse and individual needs amongst people with disabilities. Many other NGOs and INGOs also have policies or stated commitments to include disabled persons (Kett et al 2005: 7). There are also a number of international NGOs with a specific disability focus working in emergency situations, such as Handicap International, CBM, World Vision, and ADD, in recognition of the fact that persons with disability also face dangers and difficulties in conflict situations.

UN Convention on the Rights of Persons with Disabilities (UNCRPD) – Article 11:

In recognition of the great need to consider people with disabilities in situations of risk and humanitarian emergencies the new UNCRPD[20] has a specific article addressing this. Article 11 states that "all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters" shall be taken (2006). The signatories to the convention are agreeing not only to consider people with disabilities in their humanitarian assistance but to actually act. The UNCRPD puts in place an important

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[20] http://www.un.org/esa/socdev/enable/rights/convtexte.htm (accessed 4.6.11)

precedent for all its signatories to recognise the need to consider disability in emergencies, and establishes a basis around which a disability policy can be formulated.

UN Agencies:

The new UNCRPD has been adopted by UN agencies such as UNHCR who specifically mention disabled persons as one of the groups of people it works with, stating that it had included the new UNCRPD' principles in its operations and had trained staff to recognise disabilities, while also emphasising "the meaningful participation of all people of concern in project design, implementation, monitoring and evaluation in all UNHCR operations"[21]. This statement illustrates the right approach, as it aims to be inclusive throughout its operations; however, it appears that this approach has not had as much attention as other areas of their work as, along with men and the elderly, there is very little information available compared with other people they work with[22].

Although in practice it is possible to find examples of the work of UNICEF with people with disabilities in violent conflict contexts (Townsend 2008), it is currently only developing its policy on disability in its Humanitarian Policy Section and updating an info note on Disability in Emergencies[23]. The problem is that without a consistent and clear policy on disability in conflict, or in general, throughout UNICEF, or any organisation, the result is inconsistency in practice. Pavey (2010: 43) recommends that the UN family, from top to bottom, should institutionalise disability inclusiveness.

Sphere Standards and companions:

Prior invisibility and lack of consideration of persons with disability in humanitarian assistance was challenged by advocacy of ADD, which led to the revision of the Sphere Standards in 2004 to promote the inclusion of disabilities in emergencies (Kett et al.2005: 24) with that edition stating that "[i]n 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, ages, *disability* and HIV/AIDs status, affect vulnerability and shape people's ability to cope and survive in a disaster context" (own italics, Sphere Handbook 2004). Here was a major document that would reach a wide audience of humanitarian actors bringing their attention to the need to be aware of persons with disability. While not addressing the diversity within disability, it was an important step

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[21] http://www.unhcr.org/pages/4a0c310c6.html (accessed 23.2.11)
[22] Website search 27.8.11
[23] personal communication June 2011

towards recognising that persons with disability should be dealt with as part of the general population and is an important step towards mainstreaming disability in humanitarian assistance (WRC 2008: 43).

Increasing awareness has resulted in a more nuanced assessment of vulnerability and disability in the newest edition of the Sphere Standards. Recognizing the differences within the general population affected by emergencies, it acknowledges that "[n]ot all individuals within a disaster affected population have equal control of resources and power", which leads to increased vulnerability in situations of crisis but importantly it points out that "[e]xperience shows that treating these people as a long list of 'vulnerable groups' can lead to fragmented and ineffective interventions, which ignore overlapping vulnerabilities and the changing nature of vulnerabilities over time, even during one specific crisis" (Sphere Handbook 2011: 11), which further reinforces the need to mainstream disability in humanitarian assistance rather than pushing it aside as a specialist project. It acknowledges that the disabling impact of society with its physical, attitudinal and institutional barriers "prevent persons with disabilities from fully and meaningfully participating in, or benefiting from, mainstream humanitarian assistance programmes" (2011: 16) and highlights the differences amongst people with disabilities, which mean that humanitarian responses must "take into consideration the particular abilities, skills, resources and knowledge of individuals with different types and degrees of impairments" (2011: 17). All these are important steps forward in recognising the diversity of experience amongst people with disabilities and the need to consider their individual needs at the same time as recognising their presence in the general population and the need to address them as part of it. The recognition of diversity of experience is extremely important for persons with intellectual/developmental disabilities as they face their own specific challenges amongst those faced by persons with disabilities and the general population.

A companion to the Sphere Standards, the Inter-Agency Network for Education in Emergencies Minimum Standards for education in emergencies, also contains some mentions of disability, including two specific mentions of intellectual/developmental disabilities (there referred to as mental disabilities, 2010: 81, 116). It is a positive sign that alongside the increasing recognition of the importance of education in emergencies, the Minimum Standards include a section of the population that is often still excluded from education and that it strives to promote inclusion and a change in attitudes. However, despite this, UNESCO's annual Global Monitoring Report on Education for All, "The Hidden Crisis: Armed Conflict and Education" published this year contains only one reference to children

with disabilities (EFA Global Monitoring Report 2011: 146), illustrating that consciousness of the impact of conflict on children with disabilities has not really become part of general awareness, and suggesting that the attention paid to disability in last year's report had been lip-service only.

Families:

An important acknowledgment is made of the increased vulnerability of families and caregivers in the new Sphere Standards, that they "may face specific nutritional barriers" due to the care they are involved in and that it is important that they are "supported and not undermined in the care of vulnerable individuals" (Sphere Handbook 2011: 184). Nevertheless this is a rare mention of the impact on families and does not really constitute a full realisation of the increased vulnerabilities of families with disabled members. The lack of awareness of the increased vulnerabilities of families has resulted in their neglect in policy. Perhaps this is due to general lack of interest in persons with disabilities, or the tendency to focus solely on the disabled person themselves, without looking at their wider environment.

Wider issues of diversity, misunderstandings and lack of consideration

However, despite the increasing evidence of policies and guidelines amongst humanitarian agencies relating to disability in emergencies, alongside the use of the language of inclusion and the social model, a positive move forward, there continue to be issues with the policies and guidelines that exist. Not least of these is the extent of their prevalence amongst humanitarian agencies and, as shall be explored in the next chapter, with implementation and the way in which they are actually understood by those working in these agencies.

The invisibility of persons with disabilities has resulted in their continued absence from many policies and guidelines amongst humanitarian actors, as a failure to see the challenges faced by persons with disabilities results in the impression that there is no need to consider them. It appears to result from attitudes in society that mean persons with disabilities are hidden during surveys, the difficulties of collecting data in conflict, and the result that different interpretations of disability have on data, as well as attitudes of those working in humanitarian organisations which result in them not looking for persons with disabilities.

However changing attitudes and awareness have resulted in increasing recognition of the need for humanitarian policy to include considerations of disability. Organisations are starting to increasingly use the language of inclusion and the social model (Kett et. al. 2005).

This growing awareness, however, has still not spread to all. For instance, a number of humanitarian organisations contacted were unable to supply much information on their involvement with persons with disabilities and passed me on to disability specialist organisations[24]. This is a trend that occurs in practice too, as explored in the chapter below.

Additionally, the diversity of disability is not always recognised and the specific needs of people with intellectual/developmental disabilities are not raised, which may lead to a tendency for disability awareness to lead to a consideration only of the needs of those with physical disabilities for example, as they are most visible or "easiest" to assist, with people with intellectual/developmental disabilities neglected due to a lack of awareness. Recognition of diversity has already been acknowledged as necessary to identify those most vulnerable in the general population in need of assistance, so perhaps it is necessary to go a step further and recognise diversity within the groups already seen as vulnerable that lead to increased vulnerabilities. This diversity results from different impairments, but also from the differences that affect all, such as gender, ethnicity, social status and age.

Looking at the policies and guidelines which exist, we can see in the Sphere Standards that there is no specific mention to the needs of people with intellectual/developmental disabilities; although this is probably as a result of the general tendency to refer to persons with disabilities throughout the document rather than to differentiate between them. This follows a general trend of little mention of people with intellectual disabilities in policies and guidelines. Out of three guidelines read[25] for instance there were only nine specific references to people with intellectual/developmental disabilities[26]. This follows on from the lack of specific mentions in literature established in the literature review above. However, this does not necessarily mean there is a lack of interest in the needs of people with intellectual/developmental disabilities; it can arise from a lack of data, awareness, or a tendency to specialise on one disability.

Awareness and mainstreaming:

The increasing awareness of disability does not extend to all agencies working in humanitarian assistance. Or if there is an awareness of it is not easily found. For example, a search of the website of the UN Office for the Coordination of Humanitarian Affairs

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[24] Email correspondence
[25] Sphere Standards 2011 (no specific mention), INEE 2010 (2 mentions under mental disabilities), Oxfam Disability Training Manual 2003 (7 mentions including learning difficulties and mental disabilities)
[26] Also referred to as mental and cognitive

(OCHA)[27] produced no results for the word disability, let alone intellectual/developmental disability. Additionally, at a recent conference in London titled "Mainstreaming disability into humanitarian assistance: how far have we come?"[28], the fact that none of the speakers (with the exception of the Director General Army Medical Services) came from a humanitarian organisation whose main focus was not disability, perhaps indicates the answer to the question asked in the conference's title. If mainstreaming disability in humanitarian assistance has become widespread then non-disability focused humanitarian actors should have been represented; nor did there seem to be many representatives of mainstream humanitarian organisations in the audience, which may be suggestive of the level of interest they have in the matter (although there are of course many other reasons for their lack of attendance).

The focus of the presentations given indicated that the work engaged in was focused on those physically injured by the emergency, not those who were disabled prior to conflict, and seemed to be more geared towards humanitarian assistance after natural disasters rather than in the perhaps more challenging environment of violent conflict. Of course this could be chance rather than an indication of common practice (other countries mentioned briefly were affected by violent conflict) but on the point of the focus on those physically impaired by the crisis there was an acknowledgement that those who had been disabled prior to the emergency were not often considered as a priority[29], although their vulnerabilities and the disabling impact of society left them at risk. The question of "how much consideration is there of people with [intellectual/developmental disabilities] in humanitarian assistance?" was met with silence, some sheepish laughter, before an acknowledgement that it was a good question and that they tended to be very much invisible. The lack of consideration and their invisibility was attributed to the observation that people with disabilities were the lowest priority in such circumstances and people with learning disabilities were at the bottom of this too[30].

In conclusion then, the deficit of data, invisibility of persons with disability in humanitarian crises, and the low prioritisation of persons with disabilities, appear to have resulted in the lack of widespread mainstreaming of disability in humanitarian assistance. However,

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[27] http://www.unocha.org/search/node/Disability (accessed 15.7.11)
[28] Attended 24.6.11
[29] Peter Skelton, consultant for CBM, talk at the "Mainstreaming disability" seminar at the Royal Society Medicine London 24.6.11
[30] Personal communication with Pete Skelton at the "Mainstreaming disability" seminar at the Royal Society Medicine London 24.6.11

increasing awareness of the need to consider persons with disabilities due to the nature of their vulnerabilities and right to basic needs has occurred and resulted in important progress such as the inclusion of disability in the Sphere Standards. Humanitarian organisations are increasingly using the language of inclusion and the social model when it comes to disability (Kett et. al. 2005), coming in the wake of greater advocacy and stronger protections of the rights of persons with disabilities. However, mentions of disability in policy still tend to fail to recognise the diversity amongst persons with disabilities, which can result in a lack of attention towards persons with intellectual/developmental disabilities, who are the lowest of the low in terms of prioritization. Nor has there been much recognition of the impact on families. As shall be explored in the next chapter, progress on inclusion and mainstreaming of disability may exist in policy but "there are still large gaps between policy, guidance and implementation" (Kett and Twigg 2007: 94).

**<u>Humanitarian assistance and people with intellectual/developmental disabilities -
consideration in practice:</u>**

With the existence of guidelines and the increasingly widespread use of the language of inclusion and the social model in humanitarian agencies, this chapter will go on to look at the reality of disability inclusion in implementation and practice. It explores the attention paid to people with intellectual/developmental disabilities in humanitarian assistance using examples from the literature and research conducted with various actors engaged in humanitarian assistance. It will highlight the low priority of people with intellectual/developmental disabilities, even amongst other disabled persons, and explore why this is the case.

Good practice:

Excellent examples of forward thinking and good practice can be found when it comes to providing humanitarian assistance to people with disabilities, including projects that include people with intellectual/developmental disabilities. For instance, Hastie (1997) describes one Oxfam assisted project in Tuzla, Bosnia-i-Herzegovina during the war that provided a centre for children with all kinds of disabilities, a support service for their parents and carers, and co-operation with a local disability group that produced disability aids for the children in the centre. This centre introduced the social model of disability to families and practitioners and even now people there are utilizing the social model of disability[31].

In a Bhutanese refugee camp in Nepal, a training course for mothers of children with intellectual/developmental disabilities and cerebral palsy set up by Caritas to develop their self-confidence, self-esteem and skills to look after their children, has helped make them feel less isolated and lead to the formation of a mothers' support group (WRC 2008: 22).

Other examples include the work of the local NGO, Rehabilitation and Development Organisation (RaDO) working in Ethiopia in refugee camps, who are described as providing excellent access, equipment and liaison with, and involvement of, refugees with disabilities[32]. In addition, there are countless other examples that can be found in the work of international NGOs who focus on disability issues, such as Handicap International and CBM. These disability specialist INGOs are "involved in a wide range of activities including general relief and accessible reconstruction, providing emergency medical and rehabilitation

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[31] Interview with Rachel Hastie Oxfam GB 11.7.11
[32] Example provided in interview with Charlotte Balfour-Poole Save the Children UK 17.6.11

facilities, psychosocial counseling, and funding and collaborations with local DPOs" (Kett at al 2005: 8).

Problems with implementation and practice:

However, even where organisations are doing good work on mainstreaming disability into their humanitarian assistance it is possible to find examples where they are not following through with their stated commitments. For instance, despite its publication of the training manual entitled "Disability, Equality and Human Rights" and the work it has done in Bosnia for example, when responding to the Boxing Day tsunami in Sri Lanka, Oxfam built latrines that were several feet off the ground, with no ramps and therefore totally inaccessible (Kett at al 2005: 8). In addition, it no longer has a disability advisor[33].

Kett et al.'s study (2005) of disability in conflict and emergencies with a focus on tsunami-affected areas revealed that there appears to be a lack of understanding or ignorance amongst staff members as to what inclusion and the social model mean. Inclusion in practice tends to result in delegation to a specialist agency (Kett et. al. 2005: 27). The agencies may use the language of the social model and inclusion but they have "misunderstandings and do not really apply it in practice" with the tendency to still lump disabled people "under the heading of 'vulnerable groups' rather than being perceived as rights holders" (2005: 8). Occasionally it seems that the language of inclusion is being misused to justify no focused interventions for disabled people as it is argued that special attention may lead to exclusion (Kett at al. 2005: 27). Kett et al. (2005: 27) warn that the biggest danger of this lack of understanding and ignorance 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 impairment rather than disabling barriers". Perhaps this is because of the continued prominence of medical model, attitudes, or that such an approach requires less time and effort.

Kett at al. (2005: 18-19) also note that local NGOs tend to have less of rhetoric of inclusion than do the INGOs with comments such as "there aren't any disabled people around here anyway" being made. The attitudes they noted are similar to the ones detailed in the Oxfam training manual "Disability, Equality and Human Rights" relating to the reasons humanitarian agencies gave for not including disability in their programmes and generally arise from misconceptions, ignorance and prejudice (2003: 29-32) as explored below.

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[33] Email correspondence with Rachel Hastie

Despite being written in 2003 and the increased use and understanding of the social model and inclusion since then, these attitudes certainly remain common in the general public, if not amongst donors and agency staff as well, and thus are worth documenting to explain the lack of consideration and mainstreaming of disability in humanitarian assistance.

Restrictive Attitudes:

'*We need to sort out the problems of "normal" people first' (Harris 2003: 29).*

This ignores the fundamental point that "disability *is* normal: disabled people are present in every community across the globe; it is just one expression of the diversity of the human race" (original italics Harris 2003: 29). Societal norms that exclude people with disabilities warp our perception of reality and narrow our vision of what is "normal". The increased human rights legislation reinforces that they are citizens and not some "special" group[34]. Additionally, disability is likely to affect everybody at some point, temporarily or permanently, following accident or illness or as part of the aging process (Hastie 1997: 122).

'*It is not cost-effective to include disabled people…Disability is luxury we can't afford back home, let alone here' (Harris 2003: 29).*

Claiming to have only enough money to meet basic needs ignores the fact that "disabled people's basic needs *are* the basics", the same as everyone else (original italics 2003: 29). Additionally inclusion doesn't necessarily cost more, building accessible buildings only costs 1-3% more (Braithwaith et. al. 2008: 7), and "all these adaptations benefit the wider community" (Kett and Twigg 2007: 94).

Moreover, "society as a whole is poorer if disabled people are prevented from making a full contribution to the community" (Hastie 1997: 122).

'*I feel sorry for them but there aren't many disabled people here anyway, so it is not really an issue' (Harris 2003: 29).*

The problem is that due to poor statistical information, societal barriers, and cultural attitudes, disabled people are rather invisible and therefore their true numbers aren't known. For example, some humanitarian workers in Haiti could not understand why ramps were being installed in schools as they thought there were no children with disabilities, who were

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[34] Talk by David Hulme at the Disability and the Majority World Conference at MMU 7.7.11

being hidden by their families as a result of stigma[35]. With the World Report on Disability (WHO 2011) establishing that roughly 15% of the world population is disabled, it is highly unlikely that they exist in such small numbers in areas where humanitarian agencies are operating for them not to be worth considering.

This also misses the point that "[d]isability affects not only the individual but his or her family" which brings up the total number of people affected as they also become "target[s] for discrimination, and face increased poverty and hardship" (Harris 2003: 30).

'It's not in our mandate - we don't "do" disability' (Harris 2003: 29).

Disabled people tend to be seen as a separate group rather than as an element of all target populations, and therefore are seen as being catered for by specialist disability agencies, who in reality cannot meet all their needs. Therefore "[o]mitting a disability component from all programmes is akin to failing to address the needs of a group of people who account for approximately [15%[36]] of the overall population" (Harris 2003: 31), which goes against commitments to help those in need, as well as challenging the rights of people with disabilities under Article 11 of the UNCRPD. Responsibility for persons with disabilities belongs to all agencies and not just one[37]. Besides, why should specialist agencies come in to meet the basic needs of disabled people, when they could be met if those already providing them implemented more inclusive practices?

'We don't have the skills to work with disabled people' (Harris 2003: 31).

However, working with people with disabilities is not so different; "[m]any needs are the same; sometimes the approach to meeting them is different" (Hastie 2003: 31). It is not acceptable to do nothing, even if we lack the answers "all we have to do is to *ask the people concerned*" (original italics Harris 2003: 31). This attitude should change if staff become disability aware as it is largely about "changing attitudes: looking for solutions, not just seeing problems" (Harris 2003: 31). Even if the skills do not exist for a disability specific program there are always small steps that can be made that lead to greater progress on inclusiveness[38].

'We should create a special programme for them' (Harris 2003: 32).

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[35] Interview with Charlotte Balfour-Poole Save the Children UK 17.6.11
[36] New figure from World Report on Disability (WHO 2011)
[37] Interview with Charlotte Balfour-Poole Save the Children UK 17.6.11
[38] Interview with Charlotte Balfour-Poole Save the Children UK 17.6.11

When many of the needs of disabled people are "shared by other people and are not disability-specific, … - they would be best addressed in the framework of the whole community" rather than in a specialist program which is unlikely to meet all the needs of people with disabilities (Harris 2003: 32). What is needed is disability mainstreaming of humanitarian assistance, as was relatively successfully achieved with gender mainstreaming. The European Disability Forum (EDF) (original capitalisation 2002: 17) point out that a "key benefit of mainstreaming is that it can have an impact on ALL disabled people…Specific disability projects will never be able to reach all disabled people". There will still be occasions when a specialist programme may be appropriate, but this should be combined with disability inclusion in mainstream humanitarian projects, in what is known as the "twin track approach" (DFID 2000). Such an approach may have greater chance of covering all the needs of disabled people, both the ones they share with others and the ones which are specific to them.

Lack of consideration of disability:

These restrictive attitudes form part of the reason for the lack of consideration of disability in mainstream humanitarian assistance generally, let alone a consideration of people with intellectual/developmental disabilities. Aid workers exist in the same societies that disable people, and therefore it is not surprising if they pick up attitudes and mindsets that disable (Hastie 1997: 63). Work for a humanitarian agency does not negate prejudice directed towards disabled people. Nor are donors (including the general public), who have a huge influence, necessarily without prejudices. These prejudices can lead to the attitudes above and other more negative ones, resulting in the low priority of people with disabilities, which is a large part of why there has been, and continues to be, little consideration disability in humanitarian assistance.

Even where attitudes are not necessarily negative, simple ignorance and a lack of knowledge can lead to the exclusion of people with disabilities from humanitarian assistance. Especially when people with disabilities continue to remain an invisible or hidden part of the population with little voice and, in a lot of cases, little perceived worth, it is often hard to remember to factor them in unless a conscious decision is made to do so or activities like disability advocacy brings their needs to attention.

Furthermore, the medical and charitable models of disability, which may in some respects perpetuate the disabling impact of society, remain part of a lot of society's consciousness and this extends to humanitarian actors, including specialist disability

organisations (Joyce 2010: 44). The move towards acceptance of a social model is still being made and for those disability agencies set up with the medical or charitable model it can be hard to change institutional attitudes. It requires a lot of transformations that people are not always willing to make (Hastie 1997: 71).

Prioritization:

Prioritization has a great impact on the lives of people with disabilities as it dictates in part how much consideration there is of their needs. Research in Lesotho indicated that even in situations where resources were not being devoured by violent conflict, people with disabilities remained low priority, as the government feels that it "can't afford these people so why should they strain to cater for them"[39]. Such an outcome results from general negative attitudes, with people with disabilities assumed to be useless/unable do anything, and/or lack of information and understanding of the needs of people with disabilities[40]. This leads to a situation where people with disabilities "will always come last"[41] as there is a lack of political will to prioritize them. In a situation of crisis then, it is unlikely that such attitudes and prioritization will have changed, and therefore disabled people are likely to remain at the bottom of the list when it comes to meeting people's needs. For people with intellectual/developmental disabilities who have great problems in a disabling environment of proving their "worth" or ability to contribute (economically) to society, the situation is even grimmer, especially as they struggle to make their voice heard and articulate their needs, in a situation made harder for all by crisis.

Humanitarian agencies aim to meet the needs of the vulnerable and in such evaluations people with disabilities, due to their low societal prioritization and the disabling impact of society, are likely to feature highly (where they are visible that is). However, even here prioritization exists. Whether this is due to such attitudes as detailed above or because the context in which the humanitarian agencies are operating forces hard choices upon them, it is apparent that consideration of people with disabilities often comes as an afterthought rather than priority. The difficult context in which humanitarian actors are operating cannot be ignored. Just as families make the difficult decision to take the family members most likely to survive with them when fleeing from crisis situations, aid agencies are also required to make heartbreaking decisions. With limited resources sometimes the decision is made to

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[39] Interview 10.5.11 Makhetha Moshabesha Autism Society Lesotho
[40] Interview 13.5.11 M'e Monaheng LNFOD, and Interview 13.5.11 SEU Lesotho
[41] Interview 17.5.11 M'e Motsamai LSMHP, Talk by David Hulme 7.7.11

deprioritize the most vulnerable and focus on those most likely to survive[42]. In desperate conditions the greatest need is survival and people can only support the most vulnerable when they are in a position to deal with their own vulnerabilities[43]. Whether or not a difficult operating context excuses or justifies the low prioritization of people with disabilities, at least it makes it understandable, although ignoring the equal right to life of disabled people. However humanitarian work is carried out in lots of different contexts, not all of them desperate survival, and therefore humanitarian actors should be in a position to prioritize the needs of targeted populations according to whose needs are greatest, amongst whom are likely to be people with disabilities.

Despite changing attitudes, moves to inclusion, and the greater adoption of the social model, an increased consideration of disability in humanitarian action has tended to focus on people with physical and, to a slightly lesser extent, sensory impairments, with little attention paid to people with intellectual/developmental disabilities[44]. Additionally the focus on those injured by the crisis has also been to the detriment of people with intellectual/developmental disabilities as these tend to be congenital rather than acquired. Intellectual/developmental disabilities are hard to diagnose, understand and support, and they do not fit easily in a standard package[45], which might contribute to their neglect in humanitarian assistance. In the past disability NGOs have tended to specialise in meeting the needs of one particular type of impairment. For example, Handicap International was initially set up in Cambodia to meet the needs of people who had been physically impaired through conflict. As time has gone on however, and in recognition of the need that exists for all disabilities to be included, such organisations have begun working with people with a variety of disabilities. None of the major disability organisations however, was set up with a focus on intellectual/developmental disabilities, perhaps as "within disability, people with intellectual impairments come last"[46]. The fact that theirs is often not a visible disability could be an additional factor in the lack of consideration for them.

The invisibility of the lowest of the low

Why is it then, that upon encountering persons with intellectual/developmental disabilities there seems to be a tendency amongst humanitarian agencies to pass them on towards

[42] Interview Rachel Hastie Oxfam GB 11.7.11
[43] Interview Rachel Hastie Oxfam GB 11.7.11
[44] Impression given by the speakers at the "Mainstreaming disability" seminar at the Royal Society Medicine London 24.6.11
[45] Email correspondence with David Hulme
[46] Email correspondence with Peter Coleridge

specialist disability agencies? This places people with intellectual/developmental disabilities at a disadvantage. Agencies pass them on assuming that Handicap International, who tend to be associated with disabilities in emergencies are covering the needs of persons with intellectual/developmental disabilities and therefore they do not need to take care of it[47], when in actual fact Handicap International are not yet focused on meeting the needs of people with intellectual/developmental disabilities[48]. Such assumptions mean that they are falling through the cracks in humanitarian assistance.

People with intellectual/developmental disabilities face strong prejudices against them in many societies[49]. Due to the nature of their impairments they often face greater societal barriers to articulating their needs and experiences and defending themselves against abuse, as well as proving their worth in a culture that overwhelmingly values the economic benefit of people. Such an attitude even pervades the UNCRPD where the answer to the question of what society is missing out on by not including people with disabilities is "[a] larger talent pool. Persons with disabilities can contribute a wide array of expertise, skills and talents"[50] before going on to detail how employers are missing out. The value of what people with intellectual/developmental disabilities bring to human life is underplayed if they are seen as unable to contribute in economic terms, even though this is due in part to a reluctance to employ them, rather than their inability or willingness to work.

Even amongst DPOs, whose advocacy and partnerships with humanitarian agencies have proved to be very important in including disability issues in humanitarian assistance, there is a lack of representation of people with intellectual/developmental disabilities[51]. This becomes a problem when humanitarian agencies assume that disabled people's needs are homogenous and do not consult with people with intellectual/developmental disabilities and their families, thereby missing out on their specific needs. The hierarchy of disabilities within the disability movement, with people with intellectual disabilities on the bottom[52], means they tend not to be considered very highly when it comes to humanitarian assistance as they are not noticed, perceived, or brought forward as partners.

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[47] Alluded to by both Charlotte Balfour-Poole Save the Children UK and Rachel Hastie Oxfam GB
[48] Personal communication with Antony Duttine Handicap International
[49] Email-correspondence with David Hulme
[50] http://www.un.org/disabilities/convention/questions.shtml#fourteen (accessed 12.1.11)
[51] Talk by David Hulme at the Disability and the Majority World Conference at MMU 7.7.11
[52] This issue came up a few times in discussion during the Disability and the Majority World Conference at MMU 7-8.7.11

In conclusion, while humanitarian agencies may be developing policies and using the rhetoric of inclusion and the social model, progress still needs to be made towards inclusiveness and mainstreaming of disability in humanitarian assistance. Disability will continue to remain a low consideration in humanitarian assistance unless there is greater advocacy by people with disabilities. For people with intellectual/developmental disabilities and their families and carers, without advocacy and awareness raising, there remains an upward struggle to bring their specific disability issues up the agenda of humanitarian assistance. More effective and increased advocacy has to be accompanied by humanitarian agencies and others, including national governments and donors, acting to actually, and actively, listen to people with disabilities. Unfortunately it tends to be harder for people with intellectual/developmental disabilities to articulate themselves or find people willing to take the time to listen to them due to the nature of their impairments and attitudes towards them (Myerscough and Schormans 2010: v-vi). Challenges remain and opportunities for progress need to be grasped, as shall be explored in the next chapter, which ensure that people with disabilities emerge from the chaos of violent conflict in a stronger and more resilient position, leaving them less vulnerable to future crises.

<u>Analyzing the Potential for Change:</u>

The experiences of persons with intellectual/developmental disabilities of violent conflict and post-conflict situations and the lack of consideration for them in humanitarian assistance, despite some progress towards mainstreaming disability amongst humanitarian actors, may paint a bleak picture as to the situation for persons with intellectual/developmental in crisis contexts and their aftermath. Unless society changes and the barriers that serve to disable are removed, people are likely to remain vulnerable.

However, "[n]o matter how undesirable conflicts … are, they open an opportunity window" through the destruction of previous structures (Lysbakken 2011: 2). The positive examples given in the previous chapters are some instances in which it took conflict to bring about change that broke down disabling barriers in society. If the opportunity is grasped, conflict brings with it the potential for positive change. Persons with intellectual/developmental disabilities need not continue to experience conflict in the same way if their vulnerability to crisis is reduced by removing the disabling barriers in society that contribute to their disability.

This chapter explores how conflict can be used to bring about changes in attitudes, awareness and priorities, and the idea of building back better and the ways in which this can be done through disability advocacy and DPOs. It highlights the importance of the need for change in *both* the countries in which disabled people are caught up in violent conflict and amongst the humanitarian agencies working with conflict affected populations, and for the removal of the barriers highlighted by the social model of disability. Finally a number of recommendations will be made as to how the potential for change can be used to create a more inclusive society and aid structure that empowers persons with intellectual/developmental disabilities and leaves them more resilient to crises.

Recognising the potential for change:

War destroys, and while that destruction can be devastating it also bring with it opportunities to rebuild new structures (Closs 2003: 151). Conflict is about change and through it we move forward as human societies, breaking down what existed before and embracing new opportunities[53]. This is one of the reasons that Valerie Scherrer from CBM is interested in working in emergencies, because "emergency is in a way opportunities to changes. And when you work in the field of disability, where it can take years to change the attitudes of people, to build accessible schools and hospitals. When you work in an emergency you have

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[53] Interview with Rachel Hastie Oxfam GB 11.7.11

the opportunity to do that in a very short timeframe with resources, because there is money in an emergency and you've got a real chance to change the situation and the living conditions for persons with disability"[54]. Therefore, despite the negative impact on the lives of persons with disabilities that violent conflict can have, new inputs, from resources to ideas, have the potential to lead to positive changes and the removal of disabling barriers. No society can remain exactly the same after going through violent conflict but this gives it the opportunity to "build back better".

"Building back better" (Clinton 2006):

Violent conflict often results in the demolition of physical infrastructure that previously may have posed physical barriers to disabled people's access to services and general freedom of movement. This offers the opportunity to rebuild these environments in an accessible way through the concept of universal design, which looks to "produce buildings, products and environments that are inherently accessible to both the able-bodied and the physically disabled" (Atlas Alliansen 2011: 2). Rebuilding in an accessible manner costs only 1-3% more than it would to rebuild it inaccessibly (Braithwaite et. al. 2008: 7). As well as costing less than retrofitting buildings to make them accessible, accessible buildings automatically benefit others who may have mobility issues (Kett and Twigg 2007: 93). A broad approach to accessibility can also benefit everyone, as good light and acoustics, for instance, make it easier for *all* to see and hear[55].

Rebuilding also offers the opportunity to take a new approach to how buildings are used. For instance, the destruction of large institutions for persons with disabilities in Bosnia, meant that new approaches to living situations could be developed which are smaller scale and more integrated into local communities, offering persons with disabilities more opportunities and encouraging community participation (Harknett 2002: 11).

Thus it is not only physical barriers that can be removed but society's structures which can, and most often need, to be built back better. Physical barriers are not the only disabling element in people's lives; institutional and attitudinal barriers also have a strong disabling effect and should be addressed in the process of reconstruction. Addressing the post-conflict future and rebuilding of the country and society does not need to begin only in

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[54] Interview by Atlas Alliansen http://www.youtube.com/user/AtlasAliansen#p/c/0/sxp47kfuKKE (accessed 1.8.11)
[55] Personal correspondence with Susie Miles

the aftermath of the violence but can take place in the affected communities during the conflict.

The new support centre for children with disabilities in Bosnia-i-Herzegovina, that Oxfam helped set up during the war provided a much needed service in the area and introduced the social model of disability. Arza Begtasagovic (in Hastie 1997: 83), a physiotherapist at the centre acknowledges the potential for war to bring some positives with it; "I only know one thing: before the war, children in Bosnia needed a centre like this. It's sad that it took a war for us to get this". Her hope that it "will change our consciousness" has borne fruit in the fact that disability consciousness can be observed in the recent decision in Tuzla to ensure that its new buses were accessible[56]. Despite the ambitious attempt to introduce a new concept of rights of disabled people in a society embroiled in a devastating war and in transition from collectivist values (Hastie 1997: 136), the project was able to bring about a change in attitudes and help break down some disabling barriers. It is a strong argument for attempting to bring about change in protracted conflicts when able to look beyond urgent survival needs.

Refugee camps may offer more opportunities and services than persons with disabilities were able to access in their places of origin. They may be enriched by these experiences upon their return with new skills and a stronger sense of identity. For example, the Deaf community in Afghanistan returned strengthened through their experiences in Pakistan, as they came together as an Afghan deaf community in exile and developed Afghan Sign Language[57].

After the election violence in Kenya, representatives from Save the Children encountered a child with intellectual/developmental disabilities who had been abandoned by his family and tied to a tree as the local community did not know how to deal with him. They were able to talk to teachers and the local community and assist them in integrating him into school[58]. New ideas and inputs can help tackle ignorance and change attitudes.

In post-conflict contexts increased numbers of persons with disabilities, especially veterans who are perceived of as heroes, can help increase awareness, change attitudes and can lead to the re-prioritization of disability issues (Harknett 2002: 11). If wider disability issues are then addressed, those disabled prior to conflict, including most persons with intellectual/developmental disabilities, will benefit, as steps that lead to the removal of the

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[56] Interview with Rachel Hastie Oxfam 11.7.11
[57] Interview with Susie Miles 17.6.11
[58] Interview with Charlotte Balfour Poole Save the Children UK 17.6.11

disabling barriers in society leave all in less vulnerable and marginalised positions. Thus, if developed, the opportunities to make changes can have positive impacts on the lives of persons with disabilities.

The power and potential of disability advocacy and DPOs:

However these transformations do not come about without active attempts to raise awareness and advocate for change, which can come from internal and external actors such as DPOs, humanitarian agencies, and donors. Ignorance, fear, and a basic lack of awareness contribute to many of the barriers faced by people with disabilities and in order to overcome them society needs to be educated and made aware of the lives and potential of persons with disabilities so that attitudes can be changed and barriers removed. Disabled people themselves, especially when working together in DPOs, are often the most appropriate people to tackle the lack of awareness around disability. However, their work is strengthened by disability advocacy and awareness raising by people without disabilities, who aid in mainstreaming disability and demonstrating that it is an element of everyone's lives.

Successful disability advocacy strategies include meeting relevant stakeholders, lobbying, meeting with communities, training persons with disabilities in representation, producing awareness raising materials, using media such as radio, public gatherings, letter writing campaigns, bottom-up community driven approaches, collaboration with influential organisations, gaining support from experts and international institutions[59]. These help to educate communities, service providers and governments and tackle negative attitudes and ignorance. They can be influential in changing the way in which disability is perceived and prioritized and can lead to the creation of supportive disability legislation and ensuring its implementation (Abou-Habib 1999). However, all over the world, not just in conflict-affected countries, there is still a long way to go before society becomes inclusive, as we can see in the UK for instance, where "numerous independent reports [have documented] the systemic discrimination faced by people with disabilities, especially people with learning disabilities" (Emerson in Mc Veigh 9.6.11).

An important new factor has been the new UNCRPD. Where it has not been ratified, advocacy has been targeted towards encouraging ratification; and where it has been ratified advocacy is important for ensuring implementation. If adopted and implemented by countries coming out of conflict it could help to remove that society's disabling barriers.

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[59] Interviews with Autism Society Lesotho, LNFOD, SEU, LSMHP

It is important however to remember that persons with intellectual/developmental disabilities are amongst the most marginalized within the disability community and wider society. Therefore it is important to ensure that DPOs representing them are included and advocacy is carried out to highlight their position so that they do not continue to remain marginalized and invisible. Including them within the power and potential of disability advocacy can only strengthen the positions of all.

Attitudes in humanitarian organisations – the need for transformation:

While disability advocacy can help bring the necessary changes to societies affected by violent conflict that would strengthen the positions of disabled people, change is also required in humanitarian organisations working to assist those affected by conflict. The previous two chapters have illustrated the progress still needed for mainstreaming disability in humanitarian assistance and the restrictive attitudes which persist amongst some humanitarian workers. Such attitudes pose their own disabling barriers and, if they persist, will leave persons with disabilities amongst the most vulnerable elements of the population, due both to the conflict and the lack of appropriate assistance provided to them. It is not surprising however that such attitudes persist when in the countries from which humanitarian workers originate, or where humanitarian organisations are based, or of the major donors who help shape humanitarian assistance, these negative and disabling attitudes continue to exist and pervade everyday life[60]. Donors and humanitarian workers are also products of society and they may unconsciously pick up these attitudes and carry them into their work (Hastie 1997: 63).

It is therefore important to ensure that disability is "approached vertically and horizontally within aid agencies" to ensure its appropriate implementation on the ground and full support from above, and to challenge unconscious disabling attitudes carried into

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[60] Boffy, Daniel (14.5.11); Disabled people face increasing hostility from strangers, survey finds; The Guardian http://www.guardian.co.uk/society/2011/may/14/disabled-face-increasing-hostility-strangers (accessed 1.9.11)
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humanitarian aid work (EDF 2002: 19). There needs to be further dissemination of policy related to disability equality and training to increase disability awareness amongst "ALL staff" (original capitalisation EDF 2002: 19). Efforts should be made to mainstream disability into all aspects of work as has occurred with gender, so that it is not perceived as only a specialist area; although EDF (2002: 19) also recommends the appointment of someone with a "specific disability responsibility to ensure the issue does not get lost".

Projects reflect the organisation's internal structure, policy, and working practices and it is therefore "essential that the internal ethos of the institution is consistent with the intended outcome of the project in the community" (Hastie 1997: 63). Leading by example can help make great changes and the introduction of new ways of thinking and acting in relation to disability have greater resonance if they are sincere rather than a box-ticking exercise. While approaches that focus of the rights of disabled people may introduce new ideas and values that might be considered to be externally imposed[61], working together with DPOs can ensure that the work arises out of local needs.

Dealing with "prejudice and discrimination is one of the most crucial factors in an effective approach to disability" (Hastie 1997: 63) and Hastie (1997: 78) argues strongly that "[i]f challenging attitudinal barriers in society is actually part of the organisation's programme, then effective action and change will be achieved only if all staff are fully committed to the purpose". Challenging negative attitudes within an organisation may be difficult and require "a long term, consistent approach, supported by daily management" but without it "attitudinal barriers can do immeasurable damage" (Hastie 1997: 128, 63). Realising that attitudes were fundamental to the success of a project based on the social model of disability, the Oxfam program in Tuzla recruited on the basis of attitudes rather than skills because skills could be taught more easily than attitudes can be changed (Hastie 1997: 70). This does not mean however, that over time and with work, attitudes cannot be changed; but it is important for humanitarian organisations to reflect on their internal attitudes towards disability and work towards transforming attitudes and mainstreaming disability into their actions. Without transforming attitudes in humanitarian organisations the potential for change is harder to grasp and opportunities for human development and to fully meet their aims may be lost.

The "[p]rioritization of disability issues is also the responsibility of donors" and if they are supportive of mainstreaming its more likely that it will occur (Harris 2003: 56).

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[61] Personal communication with Susie Miles

Currently it is hard for organisations to justify working on disability issues if it is not part of their main mode of action[62]. DFID's approach, which states that "[w]here projects are supported they must show how they meet disabled persons needs"[63] is encouraging for mainstreaming.

Tools for change - applying the social model:

In order to realize the potential for change that conflict brings and to try and change the situation for people with disabilities, it is useful to recognise the barriers they face in society. By applying the social model of disability, society is able to reflect on itself and the ways in which it disables, and such analysis can lead to challenging and removing these barriers that "prevent full participation, inclusion and access to their rights" (Kett and Twigg 2007: 88). As opposed to other models of disabilities, it provides a fuller picture of the challenges that persons with disabilities face. Considering persons with disabilities solely in relation to the nature of their impairments does not address the wider issues that place barriers in their paths. It is not their impairments that lead to prejudice, stigma and discrimination but the reaction of others to their impairments. These attitudes and their consequences in relation to how society is organised lead to the societal barriers that hold disabled people back from reaching their full potential. Inaccessible buildings and services, lack of opportunities, discrimination, prejudice and abuse, marginalisation, invisibility and lack of consideration in humanitarian assistance stem from, *and* serve to create, disabling barriers in society that result in the vulnerability of persons with disabilities.

On the other hand, accessible buildings, transport systems, and in refugee camps, distribution points and toilet facilities, would enable persons with disabilities to access the same basic services as the rest of the population. Inclusion in schools and the running of camps and the country, would enable them to contribute and have a say over what occurs in their lives. Most importantly, positive attitudes would recognise the value and equal worth of persons with disabilities and enable them to lead lives free from discrimination and prejudice that serve to disable them and make them vulnerable in crisis situations. All barriers need to be tackled; an accessible physical environment for example will not necessarily lead to greater employment opportunities if employers are reluctant to employ them as a result of continuing prejudice. Furthermore, the social model recognises the potentials and abilities of persons with disabilities and does not cast them as helpless victims.

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[62] Interview with Rachel Hastie Oxfam GB 11.7.11
[63] Email correspondence with Amisha Patel DFID

Thus the social model of disability reveals the barriers encountered by persons with disabilities in their experiences of conflict and humanitarian assistance which need to be addressed in order to tackle the disabling impact of society. Therefore it provides humanitarian organisations and post-war recovery studies with a useful framework for understanding disability in conflict situations and offers the opportunity to understand how and where changes can and need to be made in order to decrease the vulnerability of persons with disabilities.

It encourages us to look deeper at the way in which society functions and impacts on all disabilities, and at the layers of vulnerability which exist. There are many shared experiences amongst persons with disabilities and all would benefit from the removal of societal barriers but some, such as those with intellectual/developmental disabilities, face even greater barriers due to the nature of their impairments and the ways in which they are perceived. For example, because they often find it harder to understand what is going on around them, situations like the young man with Down's syndrome murdered in the Kenyan violence because he didn't understand the tribal differences occur (Burugu (ed.) 2008: 6). It is important then to use the social model to reflect on both the differences and similarities between persons with disabilities and work towards removing the barriers that face all, so that society becomes fully inclusive.

Recommendations:

In order to seize the opportunity for change and address some of the major issues emerging from the examination of the experiences of persons with intellectual/developmental disabilities, a number of recommendations are made with the aim of creating a more inclusive society and aid structure that empowers persons with intellectual/disabilities and leaves them more resilient to crises. They seek to address the invisibility of persons with disabilities, their vulnerability as a result of the disabling impact of society and the need for greater consideration in humanitarian assistance.

Greater awareness:

Currently persons with disabilities are amongst the most invisible of all in populations affected by conflict, which has resulted in increased vulnerability as they are not reached by programs designed to alleviate suffering. By increasing awareness of the challenges faced by persons with disabilities, solutions can be found to problems such as issues concerning

access to services in refugee camps. Greater awareness of wider disability issues can also lead to the tacking of societal barriers that disable.

Gathering accurate data before, during and after conflict; engaging in awareness raising campaigns to familiarise the general public and major stakeholders with disabled people, and encouraging greater social interaction between people with and without disabilities can lead to greater visibility and increase the awareness around disability issues which can lead to solutions being found.

Transformation of attitudes:

It appears that negative social attitudes are at the root of many of the problems faced by persons with disabilities, leading to discrimination and marginalisation which makes people especially vulnerable in crisis, with Raymond Lang stating that "disability is essentially about attitude"[64]. By transforming attitudes, a new, more inclusive approach can be developed that perceives disabled people more positively. A wider societal transformation of attitudes, sometimes also amongst persons with disabilities, would make society more accessible, inclusive and empower disabled people.

A transformation of attitudes may come about through awareness raising but as these attitudes can be deeply ingrained they require long term attention and active efforts to transform them. Such efforts can come through disability equality training, dissemination and enforcement of the UNCRPD and other rights related documents, changing the way disability is talked about, as well as through increased social interactions so that disability is perceived as part of everyday life and not something different and separate.

Re-evaluating worth:

Currently people with intellectual/developmental disabilities are often under-valued in society, facing a greater struggle to prove that their life is worthwhile. This had lead to situations in which others have decided whether their life experience is of value and in extreme cases has led to euthanasia and murder (Watson and Griffiths 2009: 79). In addition, strong prejudices against them often remain, and this has lead to discrimination and neglect. Valuing people puts them up the list of priorities, strengthens their right to life, makes them more secure, in addition to recognising their inherent worth and place in the diversity of humanity.

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[64] Lecture at the Disability and the Majority World Conference at MMU 8.7.11

In order to re-evaluate the worth of persons with intellectual/developmental disabilities it is important to not treat their birth as a tragedy as "[f]rom birth, every human being has the same worth" (Mittler 2003: 32); to increase the opportunities for reaching their potential; and to recognise that the value of a person does not necessarily come from what they can contribute in monetary values but also through social interactions.

Greater advocacy:

Support towards encouraging greater advocacy, especially self-advocacy, is beneficial as it is a means of creating greater awareness, changing attitudes and strengthening the confidence of persons with disabilities. This can lead to greater societal inclusion, the creation and implementation of supportive policies, and a stronger DPO movement who can be very helpful in advising and assisting in emergency situations.

Greater advocacy can come for enabling access to media, launching campaigns, lobbying stakeholders and providing support for advocacy groups to start up. In order to overcome the under-representation of persons with intellectual/developmental disabilities encouragement should be fostered of their involvement in advocacy groups and efforts should be made to give them a greater voice and to listen to what they have to say.

'Nothing about us without us' (DPI motto [65]) – involving persons with intellectual/developmental disabilities:

A lack of knowledge about the experiences of people with disabilities makes it harder to meet their needs. It is important to involve them as they can inform those providing aid of their needs. It is especially important to recognise the diversity amongst persons with disabilities, in terms of gender, age and social status, but also of the nature of their impairments. While programs that tackle the barriers that disable may benefit all persons with disabilities, there are still individual needs which exist. Persons with intellectual/developmental disabilities continue to be under-represented amongst persons with disabilities, which results in their specific needs being neglected. Ensuring their involvement in programs would help to overcome this issue. It is important to let them speak about their experiences, but more importantly that they are really listened to.

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[65] http://www.dpi.org/lang-en/resources/topics_detail?page=956

Adoption of the social model:

Many organisations still operate with a medical or charitable view of disability, which while it may meet the necessary medical needs of persons with disabilities, fails to address the wider social issues that lead to disability (Frost 2003: vi). Adopting the social model of disability enables a deeper understanding of the issues around disability and offers a framework within which to work and create inclusive programs, and recognises that "victim assistance is not only about care and medical rehabilitation, but also about social, economic and political inclusion" (Støre 2011: 3). By recognising the strengths and potential of disabled people, the social model also encourages organisations to see them as partners, rather than as passive recipients, which can lead to the creation of more effective programs.

Through training and reflexivity, organisations can learn to use the social model to tackle the disabling barriers and work towards a holistic and longer-term solution to the problems faced by persons with disabilities in humanitarian crises.

Recruitment based on attitudes:

With negative attitudes being a crucial aspect of the barriers that persons with disability face in society, it is important that humanitarian agencies employ staff with open-minded inclusive attitudes. The success of a project can depend on staff attitudes, and leading by example can be an effective means of changing attitudes in communities in which organisations work[66]. It is much harder to change attitudes as they tend to be more deeply engrained, than it is to teach skills and therefore it could be helpful to recruit people based on their attitudes. However this is not to say that the attitudes of staff cannot be changed. It is possible to change attitudes within organisations through the adoption of disability policies, training and interaction with DPOs for example.

Just do it:

A lot of reluctance to engage with disability arises out of a fear that it requires specialist skills. Mainstreaming is perceived as too big a step to take and is often pushed towards a distant future as part of a longer process of transition. However, persons with disabilities are people like anyone else and interacting with them requires no specialist skills. Taking the time to engage with persons with disabilities and thinking innovatively and inclusively can result in programs becoming more accessible and inclusive. Realising that persons with

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[66] Interview with Charlotte Balfour-Poole Save the Children UK 17.6.11

disabilities have the same needs as anyone else and attempting to understand the challenges they face in meeting those needs can lead to the discovery of simple solutions to problems such as accessibility. By making small steps towards inclusiveness instead of putting it off as a future task that is too big to tackle now can make a big difference to people's lives. Having faith in yourself and your ability to interact with other human beings can help overcome the fear that only specialists can do something for persons with disabilities.

Of course, there is still a need amongst some people for services that require specialist skills but all their needs cannot be met by specialist services. The twin-track approach which combines mainstreaming and specialist programs is a way of including disabled people and, where needed, meeting their specialist needs that cannot be met by adaptation and inclusiveness of general programs. Just doing it, having faith, reaching out to persons with disabilities can lead to the realisation that they are as different and similar as anyone else and therefore anyone can work with persons with disabilities and consider and include them in their programs.

In conclusion, the destruction of old systems and the introduction of new ideas and practices that come about with conflict can act as a catalyst for positive change. If the potential for change is grasped in order to change society and remove the barriers faced by persons with disabilities, society can become more inclusive. Using the social model to recognise these barriers, and through disability advocacy by DPOs and other actors there is the potential for raising awareness and building back better in the aftermath of the destruction of conflict, as well as causing a transformation of attitudes in humanitarian organisations that can lead to more inclusive actions that help to further eliminate the barriers that serve to disable people.

Changing attitudes and increasing awareness are important steps towards mainstreaming disability and making considering disability when it comes to the physical environment and institutional barriers second nature. Where it remains a challenge to change attitudes, a more accessible society can lead to greater interaction with persons with disabilities, which is another route towards challenging negative attitudes. All barriers that lead to a disabling society need to be tackled; disability needs to be looked at in a holistic way and not solely through the lens of physical accessibility for example. An inclusive society, including a humanitarian aid system in which disability has become mainstreamed, would ensure that persons with disabilities were less vulnerable.

While there may be a worry that the focus on disability may lead to greater exclusion, it appears that a twin-track approach of mainstreaming and specialist disability projects can

help meet the specific needs of persons with disabilities where required, as well as including them in programs that meet their basic needs alongside the rest of the population. Adopting this approach is a way forward in tackling the barriers disabled people face. It is important to remember though, that the potential for change is only a window of opportunity for disability to become a priority. If efforts are not made it is easy for disability to fall off the agenda[67]. For the benefit of all, this should not be allowed to happen.

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[67] Interview with Charlotte Balfour-Poole Save the Children UK 17.6.11

Conclusion:

"In all wars and disasters, it is persons with disabilities that are first to die; persons with disabilities that are the first to get disease and infection; and it is persons with disabilities who are the last to get resources and medicines when they are handed out. They get treated at the bottom of the pile" (Stubbs in WRC 2008: 6)

Considering their low priority in their own communities and in humanitarian assistance and their increased risk as a result of the disabling impact of society, how have persons with intellectual/developmental disabilities coped in situations of violent conflict and how can their value be recognised so that their needs are also considered in conflict and post-conflict times? This conclusion goes on to draw out the key themes emerging from addressing the central problem and examining the experiences of persons with intellectual/developmental disabilities, as well as looking at some of the gaps and areas for further research.

What are the experiences of persons with intellectual/developmental disabilities in violent conflict and post-conflict situations?

Discrimination and prejudice, a disabling society that puts in place physical, institutional and attitudinal barriers and the nature of their impairments, which result in persons with intellectual/developmental disabilities having problems understanding and being understood, combined with their low priority and lack of voice in society, create a situation in which many persons with intellectual/developmental disabilities are disadvantaged prior to the outbreak of conflict.

A diverse group of people, who have historically faced many challenges to their right to life, people with intellectual/developmental disabilities find themselves facing death, both as direct targets and general victims of war (their risk increased due to factors such as their lack of understanding of the dangers or their inability to express themselves and others inability to understand them), injury, starvation, abandonment, deterioration in quality of life and loss of services. In addition they may face abuse (verbal, physical and sexual), discrimination and neglect in their communities, as they flee, and in refugee camps and host communities. They can become more isolated, dependent and at risk due to the effects of conflict. Their families, most often their primary carers, are also made vulnerable by their presence, due to the costs of care in both time and money, and the stigma and discrimination they sometimes face.

It is important to remember however that "[p]eople with disabilities are disproportionably vulnerable primarily as a consequence of social disadvantage, poverty and structural exclusion, rather than because of any "natural" vulnerability" (Hemmingway and Priestly 2006: 64), presenting the opportunity to reduce this vulnerability that results in heightened negative impacts of conflict.

How much consideration has there been of people with intellectual/developmental disabilities in humanitarian assistance policy?

There has been increasing recognition that there are elements of the population who require additional consideration in times of crisis as they are more vulnerable than the general population. This has lead to the formation of humanitarian policy that acknowledges the additional needs of persons with disabilities and calls for the mainstreaming of disability in humanitarian assistance.

The new UNCRPD creates a requirement under Article 11 for all necessary measures to be taken to ensure the safety and protection of persons with disabilities in situations of risk, which highlights the need for the consideration of disabled persons in humanitarian assistance. The latest edition of the Sphere Standards does this and many humanitarian agencies have begun to use the language of inclusion and the social model.

However, mainstreaming disability in humanitarian assistance still has far to go as many organisations do not have a disability policy, or perceive it as a "special" issue and not a consideration for all their work. People with intellectual/developmental disabilities are ill-served in a lot of policy as the amalgamation of persons with disabilities in general obscures them and their specific needs (Lecomte and Mercier 2009: 44).

How much consideration has there been of people with intellectual/developmental disabilities in humanitarian assistance practice?

While it is possible to find examples of good practice relating to disability in crisis, people with intellectual/developmental disabilities also face problems when it comes to the implementation and practice of humanitarian assistance. None of the major disability specialist organisations working in humanitarian crises focus on them, while there is a tendency for other humanitarian organisations to pass persons with disabilities they encounter onto these disability specialist organisations, leaving persons with intellectual/developmental disabilities to fall through the cracks. The tendency to assume disability is covered by focusing on those who become physically disabled as a result of

conflict is to the detriment of persons with intellectual/developmental disabilities, whose needs, while similar in some respects, differ in others. Their position at the bottom of the hierarchy of disabilities results in an even greater lack of consideration in humanitarian assistance.

There continue to be restrictive attitudes within humanitarian organisations that lead to the lack of inclusion of persons with disabilities in their programs, including misinformed ideas about the costs of such programs, the lack of substantial numbers, the feeling that "normal" people are the priority, and the worry that specialist skills are needed or the belief that specialist programs will meet all the needs of disabled people. This denies the fundamental normality of disability within society and the numbers affected, especially when families are factored in, the relatively low costs of accessibility which benefits wider society too, the fact that anyone can work with disabled people and that special programs cannot meet all the needs of disabled people. A twin-track approach of mainstreaming combined with specialist programs appears the most effective approach to meeting all the needs of persons with disabilities.

How can their vulnerability be decreased?

Persons with intellectual/developmental disabilities find themselves at the bottom of the already low priority disabled persons and find that their neglect prior to conflict is also reflected in the lack of consideration in humanitarian assistance, which proceeds to compound their vulnerability. However, the outlook is not completely bleak as conflict brings with it the potential for change. It is possible to change society and remove many of its disabling barriers through a process of building back better and changing attitudes in wider society. Transforming disabling attitudes in humanitarian organisations can lead to positive projects that meet the holistic needs of persons with intellectual/developmental disabilities.

Through a process of advocacy, especially on the part of DPOs and the adoption of the social model which enables reflection on the barriers in society that disable, society can change and become more inclusive. However, persons with intellectual/developmental disabilities are also underrepresented in DPOs and there needs to be efforts to enable them to express their experiences of conflict and needs, and for this to be listened to. Disability is diverse and one group does not speak for all, even when many of the same barriers are faced. Even within persons with intellectual/developmental disabilities there are many differences.

Adopting a broad and flexible attitude to disability ensures that nobody is left out (Kett and Twigg 2007: 98).

Gaps and further research:

The major gap in the research comes from the lack of direct experiences of persons with intellectual/developmental disabilities, a problem of the field in general. This invisibility can be lethal in times of conflict but with no one really looking for them they will continue to remain vulnerable. There is a need for the greater collection of information and statistics on disability so that their needs can be better served (Simmons 2010: 10).

There is also a lack of practical on the ground solutions but this dissertation is more of a call for consideration so that attempts are made to find solutions. The greatest need appears to be for a change in attitudes, as it is "attitudes [which] disable" (Coleridge 1993: 36).

It would be interesting for further research to look deeper into the reasons why persons with intellectual disabilities are the lowest of the low as this has contributed to their disproportionately vulnerable position. The effects of having a member with disabilities on a family also would benefit from further examination, as would a consideration of the local community and national government responses. The impact of donors and their understanding of the importance of disability on programmes in the field should also be investigated. Examining indicators for inclusion would aid in monitoring and evaluation and provide a more accurate impression of the extent to which disability policy was being implemented (Kett and van Ommeren 2009).

Persons with intellectual/developmental disabilities have had to cope with disproportionately negative experiences of conflict. The "assumption that support for general populations will automatically benefit disabled people is false: disable people do not have equal access to resources and opportunities" (Harris 2003: 49). Considering their needs and the needs of persons with disabilities in general, through inclusiveness and mainstreaming, would create "a higher quality society for everyone, not just disabled people; as society that embraces diversity, promotes community solidarity, enables people's potential and protects those who are vulnerable" (EDF 2002: 17). It is undeniable that persons with intellectual/developmental disabilities have important differences but these should not be seen to be due to the "deficient nature of the individuals concerned" (Ryan 1987: 29). Recognition of the inherent equal worth and dignity of each human being, despite their differences, would result in their

inclusion in humanitarian assistance. Having forgotten for so long about the plight of people with intellectual/developmental disabilities in conflict, it is important to start finally paying attention.

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David Felce – Welsh Centre for Learning Disabilities

David Hulme – University of Manchester

Doreen Woodford – Deaf Africa Fund

Elin Fjestad – Atlas Alliansen

Eric Emerson – University of Sydney

Frances Stewart – University of Oxford

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Appendix 1: Questionnaire devised for persons with intellectual/developmental disabilities

My name is Brigitte. I am a student at university. I read and write a lot about wars.

I am writing about people with intellectual disabilities in war.

No one has been asking people with intellectual disabilities about what life is like in war.

I think it is important for us to know about people with intellectual disabilities in war.

Your story about war is important. Your story can help other people.

Would you like to talk about your life during war?

What did you do?

What did you see?

What happened to you?

Did you have to leave your home?

Who is helping you?

What are they doing for you?

Thank you for your help. It was great to hear your story.
Brigitte Rohwerder

Appendix 2: United Nation Convention on the Rights of Persons with Disabilities

Downloadable in pdf format on
http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf

On line version http://www.un.org/disabilities/default.asp?id=259

Selected articles:
Article 5
Equality and non-discrimination
1. States Parties recognize that all persons are equal before and under the law and are entitled without any discrimination to the equal protection and equal benefit of the law.
2. States Parties shall prohibit all discrimination on the basis of disability and guarantee to persons with disabilities equal and effective legal protection against discrimination on all grounds.
3. In order to promote equality and eliminate discrimination, States Parties shall take all appropriate steps to ensure that reasonable accommodation is provided.
4. Specific measures which are necessary to accelerate or achieve de facto equality of persons with disabilities shall not be considered discrimination under the terms of the present Convention.

Article 10
Right to life
States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.

Article 11
Situations of risk and humanitarian emergencies
States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.

Appendix 3: Sphere Standards – extracts relating to disability

Persons with disabilities:
The World Health Organization (WHO) estimates that between 7 and 10 per cent of the world's population – including children and older people – live with disabilities. Disasters and conflict can cause increased incidence of impairment and subsequent disability. The UN Convention on the Rights of Persons with Disabilities (CRPD) defines disability as an evolving concept that results from the interaction between persons with impairments (which may be physical, sensory, intellectual or psychosocial) and the attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others. It is, therefore, the presence of these barriers that prevent persons with disabilities from fully and meaningfully participating in, or benefiting from, mainstream humanitarian assistance programmes. The new CRPD makes specific reference to the safety and protection of persons with disabilities in conflict and emergency situations (Article 11).

Persons with disabilities face disproportionate risks in disaster situations and are often excluded from relief and rehabilitation processes. Such exclusion makes it more difficult to effectively use and participate in standard disaster support services. Importantly, persons with disabilities are a diverse population including children and older people, whose needs cannot be addressed in a 'one size fits all' approach. Humanitarian responses, therefore, must take into consideration the particular abilities, skills, resources and knowledge of individuals with different types and degrees of impairments. It is also important to remember that persons with disabilities have the same basic needs as everyone else in their communities. In addition, some may also have specific needs, such as replacement of aids or appliances, and access to rehabilitation services. Furthermore, any measures targeting persons with disabilities must not lead to their separation from their family and community networks.

Finally, if the rights of persons with disabilities are not taken into consideration in humanitarian responses, a huge opportunity is lost to rebuild communities for all people. It is essential, therefore, to include persons with disabilities in all aspects of relief and recovery. This requires both mainstreamed and targeted responses.

Humanitarian assistance:
The **right to receive humanitarian assistance** is a necessary element of the right to life with dignity. This encompasses the right to an adequate standard of living, including adequate food, water, clothing, shelter and the requirements for good health, which are expressly guaranteed in international law. The Sphere Core Standards and minimum standards reflect these rights and give practical expression to them, specifically in relation to the provision of assistance to those affected by disaster or conflict. Where the state or non-state actors are not providing such assistance themselves, we believe they must allow others to help do so. Any such assistance must be provided according to the principle of **impartiality**, which requires that it be provided solely on the basis of need and in proportion to need. This reflects the wider principle of **non-discrimination**: that no one should be discriminated against on any grounds of status, including age, gender, race, colour, ethnicity, sexual orientation, language, religion, **disability**, health status, political or other opinion, national or social origin.

Vulnerable:
Throughout the Handbook, 'vulnerable' refers to people who are especially susceptible to the effects of natural or man-made disasters or of conflict. People are, or become, more vulnerable to disasters due to a combination of physical, social, environmental and political factors. They may be marginalised by their society due to their ethnicity, age, sex, disability, class or caste, political affiliations or religion. A combination of vulnerabilities and the effect of an often volatile context all contribute to people being vulnerable for different reasons and in different ways. Vulnerable people, like all those affected by disaster, have various capacities to manage and recover from disasters. A thorough understanding of vulnerable people's capacities and the barriers they may face in accessing humanitarian support is essential for a response that meets the needs of those who need it most.

A mention of carers:
Caregivers and those they are caring for may face specific nutritional barriers, e.g. they may have less time to access food because they are ill or caring for the ill, they may have a greater need to maintain hygienic practices which may be compromised, they may have fewer assets to exchange for food due to the costs of treatment or funerals and they may face social stigma and reduced access to community support mechanisms. It is important that caregivers be supported and not undermined in the care of vulnerable individuals; support offered should address feeding, hygiene, health and psychosocial support and protection. Existing social networks can be used to provide training to selected members of the population to take on responsibilities in these areas (see Protection Principle 4 on page 41).

Appendix 4: INEE Minimum Standards – extracts relating to disability

People with disabilities: The needs of people with physical and visual disabilities should be carefully considered in the design of education facilities. Entrances and exits need to accommodate people in wheelchairs or using other assisted-mobility devices.

Classroom space and furniture, and water and sanitation facilities, should meet the needs of people with disabilities.

When identifying sites and reconstructing education facilities, cooperation at local and national levels is recommended with organisations representing people with various types of disability, parents of children with disabilities and youth with disabilities.

Building for the long term: Education personnel and communities should participate in trainings on roles and responsibilities for the long term. These may include trainings on resource mobilisation and management, the maintenance of facilities, disability awareness and special measures to ensure the participation of children and youth.

Diversity should be considered in the development and implementation of educational activities at all stages of emergency through to recovery. This means including learners, teachers and other education personnel from different backgrounds and vulnerable groups and the promotion of tolerance and respect. Specific aspects of diversity may include:
- gender;
- mental and physical disability;
- learning capacity;
- learners from diverse income groups;
- classes containing children of different ages;
- culture and nationality;
- ethnicity and religion.

Risk: the product of external threats such as natural hazards, HIV prevalence, genderbased violence, armed attack and abduction, combined with individual vulnerabilities such as poverty, physical or mental disability or membership in a vulnerable group.

Appendix 5: World Report on Disability 2011 - WHO

Box 2.3. Assistance for people with disabilities in conflict situations
Armed conflict generates injuries and trauma that can result in disabilities. For those incurring such injuries, the situation is often exacerbated by delays in obtaining emergency health care and longer-term rehabilitation. In 2009 in Gaza an assessment found such problems as (*81*):
■ complications and long-term disability from traumatic injuries, from lack of appropriate follow-up;
■ complications and premature mortality in individuals with chronic diseases, as a result of suspended treatment and delayed access to health care;
■ permanent hearing loss caused by explosions, stemming from the lack of early screening and appropriate treatment;
■ long-term mental health problems from the continuing insecurity and the lack of protection. As many as half of the 5000 men, women, and children injured over the first three weeks of the conflict could have permanent impairments, aggravated by the inability of rehabilitation workers to provide early intervention (*82*).
In situations of conflict, those with disabilities are entitled to assistance and protection. Humanitarian organizations do not always respond to the needs of people with disabilities promptly, and gaining access to persons with disabilities who are scattered among affected communities can be difficult. A variety of measures can reduce the vulnerability of persons with disabilities including:
■ effective planning to meet disability needs by humanitarian organizations before crises;
■ assessments of the specific needs of people with disabilities;
■ provisions of appropriate services;
■ referral and follow-up services where necessary.
These measures may be carried out directly or through mainstreaming. The needs of families and carers must also be taken into account, both among the displaced population and in the host communities. In emergencies linked to conflicts, the measures need to be flexible and capable of following the target population, adjusting quickly as the situation evolves.