

'In His image'

Prisma vision paper on people with disabilities
in development cooperation



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August 2010

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ABBREVIATIONS

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Abbreviations

CBR	Community Based Rehabilitation
CSO	Civil Society Organization
DCDD	Dutch Coalition on Disability and Development
DPO	Disabled People's Organization
FBO	Faith Based Organization
ICF	International Classification of Functioning, Disability and Health
MDG	Millennium Development Goal
NGO	Non Governmental Organization
PWD	People/persons with Disabilities
WHO	World Health Organization

Introduction

Vulnerable groups of people continue to form the main focus within different programmes of several Prisma members, and of the ICCO-Alliance. When Prisma member organizations decided to collaborate within the framework of the Dutch co-financing system MFS, they also agreed to elaborate on their vision concerning vulnerable groups. Bearing in mind the expertise some of the Prisma member organizations have in the area of disability, we decided to write a vision document on people with disabilities.

A working group was established consisting of staff from two member organisations (the Leprosy Mission and Dark & Light Blind care) and a Prisma staff member. This document has been reviewed by other Prisma staff members and by representatives of some other member organizations (Dorcas, Woord en Daad and Tear) and a referent of the organization 'Op weg met de ander', a reformed association of and for people with disabilities. This document is the result. It has been accepted by the General Meeting of Prisma member organizations as a Prisma vision paper.

The main aim of this vision paper is to encourage and support Prisma member organizations and their partners, as well as other organizations, in developing policies and programs that are inclusive to people with a disability.

Houten, 25 August 2010

H. Jochemsen, PhD
General Director Prisma

Chapter 1 The need for a Prisma policy

1.1 People with disabilities: a forgotten group in development cooperation?

In the 1970s many organizations active in development cooperation were working in the field of disability, especially on technical assistance. However, in the 1990s the Dutch government, as well many organizations in development aid and training institutes lost special attention for policy on disability. Reasons for this policy change included¹:

- High expectations of Community based rehabilitation (CBR) as a strategy to increase the targeted number of people with a disability with fewer resources than institutional rehabilitation, were not realized
- Abandoning of the 'target group approach'
- Large decrease in expatriate physiotherapists and ergo therapists, with the knock on affect of little advocacy and lobby activities of returnees from these professions
- Emergence of the human rights perspective for development policy, followed by the sustainability- and environmental perspective, and then the security perspective. Within these policy perspectives, attempts to put the role of disability in poverty on the agenda have not succeeded.

Largely as a result of these factors the majority of innovative disability projects were cut back. Only a few institutional relations remained to be financed.

This means that in our view of development cooperation, people with a disability do not get the attention they deserve as members of the human family. For that reason Prisma members and the Prisma staff decided to draw a vision paper on this topic.

1.2 Prisma and policy

In general the Prisma organizations are a positive exception to the trend mentioned above. There is still much cooperation with Faith Based Organizations (FBOs) and Civil Society Organisations (CSOs) at the grassroots level that pay special attention to the most vulnerable groups, including people with a disability. Not every organisation however has a clear policy backing its activities in this area.

Several building blocks for policy on disability were already put forward by DCDD. It is important for the purpose of this paper to explicitly mention the following:

- In societies where poverty and/or large insecurity prevail, 90% of the physical disabilities can be prevented. Too often there are at least 10 times as many disabilities as in a western-European society, due to poor or absent mother-and child care, poor or absent services, stigma and discrimination and the impact of domestic and sexual violence.
- People with a disability have the same human rights as every person: right to life, individual rights, citizenship rights and social rights.
- People with a disability are entitled to full participation in society, as far as their strengths and capabilities enable them. Stigma and discrimination must be avoided and adequate basic services should be accessible.

¹ Christina de Vries (2008), *Suggesties en overwegingen voor de ICCO-Alliantie (TtB) ten aanzien van een disability-programma*. Utrecht: IC Consult.

1.3 In His image

This vision paper is titled “In His image”. Prisma recognizes that disabled people, just like other vulnerable people, in general do not have equal possibilities. Nevertheless, (as Christian organisations) it is our strong belief that they are created in the image of God just like every human being, and hence are full members of the human family with equal dignity and rights (see Chapter 4). Therefore, Prisma wants to further their inclusion in all aspects of social life as they would wish for themselves. In many societies disabled people, alongside other groups, are suffering injustice by mechanisms of exclusion and stigmatization. In this vision paper we focus on people with a disability, but this does not imply that people with a disability are the only group of vulnerable people.

Prisma promotes a policy development process that dedicates explicit attention to vulnerability. This regards the larger group of vulnerable people, including disabled people but also other groups like women, children and people living with HIV, depending on the context. Since a few Prisma members specifically focus on people with a disability the production of a vision paper on disability has been given priority. Other organisations can take advantage of the special expertise that some Prisma members already have in this field.

1.4 Structure of the document

In chapter 2 we present an explanation of the problem and the most important views on disability. Then, in chapter 3, cultural and religious views on disability are explored. Chapter 4 explains more deeply the Christian view and in Chapter 5 policy options for the coming years are laid out.

Chapter 2 Disability: describing the problem

2.1 Facts and figures

According to figures from WHO and UNFPA 650 million people or 10% of the world's population have an intellectual, mental, physical, sensory or auditory impairment. About 70% of these people are living in developing countries and 87% of these people are children. Of these children 90% are not attending school. For poverty eradication we must therefore assume that a substantial proportion of all people living below the poverty line have a disability, and that the vast majority of these are minors. With a demographic shift in many regions towards older populations, evidence suggests that disability, usually due to chronic disease, is an important public health problem from age 45 years onwards. Major causes of age related disability are neuropsychiatric disorders (the growing prevalence of conditions such as Alzheimer's disease), sight and hearing impairment, osteoporosis, arthritis, diabetes, and injury².

The World Bank estimates that 20% of the poorest in the world live with a disability. It should be noted however that not all impairments lead to limitation of participation in society. Therefore not in all situations measures need to be taken.

More reliable and comparable figures on the number of people with disabilities in developing countries are scarce and as a result, people with a disability are barely visible from a statistical perspective. It is clear that without paying attention to the structural position of people living with disabilities (who are represented in all ranks of society) the MDGs can not be achieved, e.g. in terms of eliminating absolute poverty, prevention of infant mortality and education for all (MDG 1, 2 and 4).

2.2 Causes and backgrounds

Disability is not only a cause of poverty but it is also a result of poverty. People can become disabled by a combination of poor nutrition, hygiene and sanitation, and of bad quality drinking water due to e.g. environmental pollution. Other important causes are diseases, lack of or inadequate access to (preventive and curative) health care facilities, heredity factors, brain damage due to lack of oxygen before, during or shortly after birth, complications during and after pregnancy and the misuse of drugs and injections. Also late or incorrectly treated accidents (e.g. traffic or by the use of fire in and around the house) and dangerous working and living conditions are potential causes of disability. Disabilities can be caused by war and (ethnic, cultural or religious) conflicts and their aftermath and consequences in the form of unexploded munitions, landmines, psychological trauma due to torture, mutilation, sexual abuse or (systematic) rape. In addition, disabilities can also be caused by (natural) disasters, alcohol and drug abuse and complications in cultural practices such as female genital mutilation among women and girls.

The consequences for people with disabilities are numerous, certainly for those with

² CSDH (2008). *Closing the gap in a generation: health equity through action on the social determinants of health. Final Report of the Commission on Social Determinants of Health*. Geneva, World Health Organization, p. 97.

disabilities in developing countries. Poverty, and social and economic exclusion, lead to minimal chances of the good development of one's abilities. They have almost no access to affordable (reproductive) health, rehabilitation and education services and to paid work. Housing or confinement conditions (sometimes even in overcrowded prisons) are poor. Mutilation, often in connection with forced and organized begging, reduces those chances even further. And it is important to realize that the consequence for some is murder.

The position of women and girls with a disability is more acute than that of men and boys. Girls with a disability are often discriminated against within their own families; they receive less food and care, access to health care, rehabilitation and education and chances of paid work are even lower than the chances for boys with a disability. In addition, within the household or at school they run increased risks of becoming victims of abuse, exploitation, sexual abuse and rape, sometimes leading to unintended pregnancy or forced sterilization, and other forms of persistent gender-based violence. Their marriage chances are lower than those of men with disabilities. Studies show that women with disabilities are at increased risk of HIV infection.³

2.3 Classification of disabilities

Under the UN Convention on the Rights of Persons with a Disability, disability is recognized as an evolving concept, resulting "from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others".⁴ Disability is broader than the word handicap, which is often experienced as stigmatizing. DCDD defines disability according to the social model whereby restrictions are located in the environment: not the person is limited, but the environment; social and economic facilities are neither designed nor suitable for participation of people with disabilities.

Categories of restrictions or limitations are distinguished in different ways, mainly along the lines of the so called medical model (see paragraph 2.4). The Liliane Fund does this in the following way:⁵

- Problems with physical mobility, e.g. as a result of polio, amputation or neurological disorders
- Problems with vision, e.g. (partial) blindness, cataract, trachoma
- Problems with hearing and speech, e.g. (partial) deafness, aphasia
- Learning disabilities (people with a cognitive disability)
- Chronic seizures like epilepsy
- Cosmetic defects, e.g. cleft lip (cheiloschisis)
- Double or multiple disabilities; children with both a physical and a mental impairment (including brain damage)
- Other, used for exceptions

Additional to the above mentioned problems with vision, hearing and speech problems, difficulty in moving, seizures and learning disabilities, in their manual for CBR the WHO distinguishes those suffering from problems with feeling and deviant behaviour (strange

³ Groce, N. (2005), *HIV/AIDS and Disability*. Health and Human Rights. 8:2;215-225, and World Bank. (2004) *Capturing Hidden Voices: HIV/AIDS and Disability*. Washington: The World Bank Group.

⁴<http://www.dcdd.nl/reader/pdf/A1/CRPD-English.pdf>

⁵ <http://www.lilianefonds.nl/>

behaviour).⁶

The International Classification of Functioning, Disability and Health, better known as ICF⁷, is the conceptual framework of the WHO used to measure health and disability at both individual level and population level. It is a universal classification of disability and health, for use in the health sector and other related sectors, accepted by 191 countries. It is a classification of areas that help to assess changes in the function and structure of the body to describe what a person with a certain health condition can do in a standard environment (his or her level of capacity) and what that person actually does in the usual environment (his or her performance level). Within the ICF, the term functioning refers to all bodily functions, activities and participation, and disability is a similar broad term for impairments, limitations in activities and in participation.

2.4 Models

In some developing countries, particularly in rural communities, disabilities are regarded as fate, a result of bad deeds from the past, a penalty of higher powers for errors and/or bad behavior of parents and ancestors, black magic, witchcraft or supernatural forces. This justifies stigma in these societies. Not only stigma of others but also self-stigma is a problem. Mental disabilities are especially surrounded by stigma. On the other hand, sometimes disabilities are viewed positively as a gift or sign. In some societies, such as Cambodia, Angola, Eritrea and Mozambique, disabilities caused by war are seen as a sign of honor.

Sadly however, the majority of people with disabilities in developing countries live in the margin of society. Disability is often linked to discrimination and poverty. These problems cause the experienced loss of dignity, poor health (especially women and small children) and poor education for children.

There are many different ways in which disability is interpreted. Several models show how societies look at disabilities. The most common models are mentioned here:

- The **moral model**: disability is the result of sin; the impairment or restriction is seen as punishment or as fate and therefore no redemption is possible for the victim. The moral model sees people with disabilities as victims instead of responsible human beings.
- The **medical model**: disability is an individual problem caused by illness, trauma or health conditions. It is an anomaly or disease that has to be cured by medical intervention and/or adjusted using medical rehabilitation. The body is seen as a biological system that can be healed or repaired.
- The human rights or **social model**: disability is caused by social, cultural, economic and environmental factors, the main problem being discrimination and exclusion of people with a disability by society. The response is to eliminate those obstacles. Medical intervention is seen as one of the aspects that need attention which thus enables people with disabilities to fully participate in society. This model doesn't separate between body and mind or body and society. It focuses mainly on power relations.

⁶ Helander, E. et al (1989), *Training in the community for people with disabilities*. Geneva: World Health Organisation.

⁷ WHO (2002), *Towards a Common Language for Functioning, Disability and Health: ICF, The International Classification of Functioning, Disability and Health*

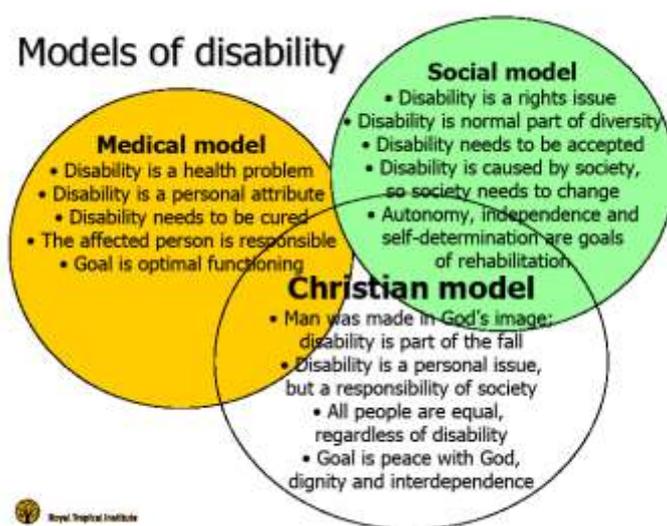
In many developing countries the moral model prevails among the population. At the same time people and institutions involved in care for people with a disability often use the medical and social models to explain and classify disabilities.

The following table summarizes the major differences between these two views:

Medical model	Social model
Individual problem	Social problem
Medical care	Social integration/inclusion
Individual treatment	Social actions
Professional support	Individual and collective responsibility
Intervention in individual	Intervention in and of environment
Behaviour	Attitude
Care	Human rights
Rules health care	Politics/policies
Individual adjustment	Social change

- In Europe and the US this social model is elaborated into the **citizenship model**. This is an inclusive social model emphasizing abilities, individual skills, personal autonomy and social solidarity. The main elements of the citizenship model are: that people with a disability have the same rights as every other citizen, that they can make their own choices and that they will receive support in order to get access to the necessary knowledge, means or people that enable them to fully participate in society. It does not only focus on rights but also on duties and responsibilities just as they apply to all citizens.

- In the literature, a model has been proposed based on a Christian perspective on disability. This model looks at where and how Christian principles deal with main elements of the medical, the social and the citizenship models. In fact one could say that the Christian model provides a theological underpinning and interpretation of central elements of the other three models. A brief presentation of some of the models as found in literature is given below.



Source: W.H. van Brakel, Royal Tropical Institute (KIT).

From an analysis of these models, Prisma, together with most organizations working with and for people with disabilities, prefers the citizenship model. In this model the individual is not removed from his or her environment, nor from society at large, as a political community of which the members have rights and responsibilities. However the medical aspects should not be forgotten. It remains important to provide medical care with staff that respect people and consults them about their needs. In the social model, people with severe limitations run the risk of getting insufficient care. In many countries, good medical care is a prerequisite for the ambitions of people with disabilities. It is the first step towards empowerment. Where good quality medical care is available and accessible, people organize themselves and it has been found that sometimes disabled people's organizations (DPOs) originate from self help groups.⁸

Acknowledging *the rights* of the weak and the poor (see also paragraph 4.5) does not exclude compassion and charity. Many of the Prisma organizations have a history in which acts of compassion were central to their activities. Even today this attitude is important. Compassion is the act of mutual aid and solidarity, evoking and promoting justice. At the same time it is realized that in certain situations just focussing on charity can hamper the promotion of justice.

Since Prisma is a Christian organisation, we will interpret and underpin the citizenship model from a Christian view of life. The main notions of this view, important in this context will be presented in chapter 4.

2.5 Active organizations and networks

2.5.1 UN Convention on the Rights of Persons with a Disability

The UN Convention on the Rights of Persons with a Disability asserts the rights to education, health, work, adequate living conditions, freedom of movement, freedom from exploitation and equal recognition before the law for persons with disabilities. In addition, the Convention's Optional Protocol allows individuals to petition an international expert body with grievances. The Convention and the Optional Protocol entered into force in May 2008. This has implications for the Dutch development cooperation policy. The Netherlands has not yet ratified the convention. However, the Netherlands signed the convention on March 30, 2007 and the government promised that ratification would follow during the term of the next government (in office 2007-2011).⁹ The UN Convention is already calling for changes in Dutch development cooperation policies. Under the convention, the Netherlands is obliged to follow an inclusive policy for development cooperation, a policy with due attention for people with disabilities. In the last policy of the Department for development cooperation (2007), this group is hardly reached.

2.5.2 Dutch Coalition on Disability and Development (DCDD)

DCDD is a coalition in which persons (individual members) and organizations (institutional members) operating in the field of disability, development cooperation and service-provision are united. DCDD has an extensive volunteer network with working groups and advisory groups on different themes. These themes include: inclusive education, community based rehabilitation, HIV and AIDS and Human Rights. DCDD is registered as a foundation with a board which consists of members of the coalition.

⁸ Cornielje, H. et al. (2008) An update on community based rehabilitation for leprosy practitioners (editorial). In: *Leprosy Review*. Vol. 79: 1-3

⁹ However the cabinet that started in 2007 fell in 2010 without the convention being ratified yet.

DCDD is committed to inclusion and social participation of people with disabilities in situations of poverty and exclusion. DCDD works from a perspective of human rights and solidarity. Its core targets are¹⁰:

- Awareness-raising regarding the position of people with disabilities and support for inclusive development cooperation policy
- Exchange and cooperation between people and organisations who are active in disability and development cooperation
- Innovation and change of policy towards inclusive development cooperation

As an association Prisma is a member of DCDD. In addition, some Prisma organizations are institutional members themselves or staff members of Prisma organizations are individual members.

2.5.3 Other organizations and web links

For other organizations in the field of disability and development such as the International Disability and Development Consortium (IDDC) please refer to the website of DCDD:

<http://dcdd.nl/default.asp?action=article&id=3235>

Several countries in Asia and Africa have their own national organizations in the field of disability.

Disabled Peoples' International (www.dpi.org) is a network of national organizations or assemblies of disabled people, established to promote human rights of disabled people through full participation, equalization of opportunity and development.

Affiliated regional networks are:

- In Asia: Disabled Peoples' International Asia-Pacific (DPI/AP)
- In Africa: the Pan African Federation of the Disabled (PAFOD)
- In South America: La Region Latinoamericana de la Organización Mundial de Personas con Discapacidad (RLOMPD).

The Global Partnership for Disability and Development (<http://www.gpdd-online.org/>) is a new initiative to accelerate inclusion of people with disabilities and their families into development policies and practices. It was formed to increase collaboration among development agencies and organizations to reduce the extreme poverty and exclusion of the substantial number of children, women and men with disabilities living in poor countries. Another interesting site in this field of disability and development is www.inclusion-international.org

The World Council of Churches has its own network. The Ecumenical Disabilities Advocates Network (Edan) with as its main purpose advocacy for inclusion, participation and active involvement of persons with a disability in the spiritual, social, economic and structural life of church and society.¹¹ Furthermore, some regional and interregional organizations pay attention to mainstreaming of disability in their working groups. An example is EU-CORD.

In different ways online discussion groups discuss theological aspects of disability. More about these groups in annex 3.

¹⁰ <http://www.dcdd.nl/default.asp?action=article&id=3233>

¹¹ <http://www.oikoumene.org/en/programmes/unity-mission-evangelism-and-spirituality/just-and-inclusive-communities/people-with-disabilities-edan.html>

Chapter 3 Religious and cultural beliefs about disability

3.1 Basic themes in culture and religion

Cultural and religious norms and values directly affect perceptions on disability. People with a disability at first sight seem to be 'different', or even odd. Furthermore, disabilities confront people with their own vulnerability which they prefer not to face. This easily frustrates an open attitude and acceptance of such persons. On the other hand people with a disability are often living with urgent questions like 'why?' or 'why me?' Answers, or rather ways of dealing with such questions are found in religion and culture. Worldwide major differences can be observed between cultures and religions with regards to disability. For outsiders, and often also for humanitarian aid workers, the perception in other cultures of living with a disability seems inscrutable. Cultural and religious views often influence the choice or even access of treatment or rehabilitation.

What is the influence of culture or religion on the position of people with a disability? In this chapter an observation will be made regarding a predominant cultural view on disabilities and subsequently deal with some major religious influences. It should be realized that religious views in the lives of people are generally inseparably intermingled with cultural influences.

Culture

If it is true that ancient traditions are based on a barter/trade of favours and services between bosses and clients, people with a disability are facing a major problem. Their position is weak and emancipation is far ahead. For rulers, people with disabilities are not a factor of any significance when it comes to their own interests. The environment is also often restrictive. In many cultural settings avoidance, stigma and ignorance are dominating reactions.

Religiously inspired views

Human beings are religious beings in the sense that they try to interpret and give meaning to their life and experiences by relating them to what they consider to be the ultimate determining reality. In most cultures, that determining reality is a spiritual world. Hence the occurrence of disabilities and the experience of a disability provokes questions that people try to deal with in the light of their religion. This pertains to existential questions like: Why me, or, my child, husband, wife? But also to questions regarding causes of disabilities, the role of gods, sin and guilt, fate, doom and predestination? In the way religions deal with these questions, there are roughly three basic patterns which can be distinguished.¹²

a) Firstly, religious traditions historically have wrestled with the question about disability and its *association with sin*. Is it punishment for mistakes made by the person his/herself or his/her parents? Or is it a curse? "Did I deserve this? I have always tried to live well", is the question people are asking when misfortune hits. It is often suggested that something is standing between the person with a disability and God or the gods. Why else would

¹² Partly based on Kool, Jacqueline (2002) *Gedoodverfde kwaaddoener of spirituele superheld? Over religie en beeldvorming rond handicaps*, Lecture held during seminar of the Liliane Fund and DCDD: Wanneer spreekt men van een handicap? Hoe culturele en religieuze waarden van invloed zijn op revalidatie in ontwikkelingslanden, 29 november 2002.

God turn His back on that person? This kind of thinking (both internally within the person with a disability as well as from his or her environment) is very judgmental and condemning for people with disabilities: they are left to themselves, and blamed for something they can do nothing about. This can lead to feelings of shame in themselves, but also in family members, causing them to hide their shame, implying the physically hiding of the people with disabilities, as much as possible.

b) A second theme is a certain *view on suffering*. Religions devote much attention to suffering, because suffering occupies people's mind a great deal. Disability and disease are automatically associated with, or defined as, a great suffering, which ideally should be carried courageously and especially also cheerfully. Many people with disabilities feel that the outside world sees them as victims of bad fate, or as heroes when they attempt to live as much as possible a 'normal' and meaningful life, by actively engaging in society.

c) The third pattern is the *ideal of charity*. In the Judaeo-Christian tradition, but likewise in other religions, people are encouraged to do good to those who are less privileged than themselves. We have already seen that addressing the rights of the weak and the poor (see also section 2.4 and 4.4) does not exclude charity. Charity as an expression of compassion has meant, and means a lot to people, who are dependent on others. But in addition to its good intentions and actions, charity also runs the risk of being paternalistic and arbitrary. People with disabilities are often not involved in deciding what other people's charity would mean for them. In this way, they are denied the ability and opportunity to indicate for themselves what they need, and who they want or do not want to attend to them. Not recognizing this means maintaining power inequality and keeping people with disabilities dependent.

3.2 Notions on disability in Islam and Hinduism

In this section we present some major views of Islam and Hinduism on disability. A presentation of a Christian view will be given in the next chapter. We choose these two world religions in addition to Christianity since Prisma members are working in countries in which these are the major religions. We point out that there can be a difference between the official teachings of a religion and the practice of its adherents in a certain historical and cultural situation.

Islam

The Koran requires acceptance and a constructive attitude to life. *Islam* believes that Allah knows and sees that people with a disability have a problem. A Muslim, in principle, does not wonder "Why has Allah done this to me?" but he says "What should I do with it?" He already knows in advance that whatever happens to him is with the consent and knowledge of Allah, it is the person's fate (*inshallah*). People around the person with a disability realize that they have something the other does not have, so they are commissioned to help the other. Assisting people with a disability is a part of religion, a duty.

In Islam there is a concern about purity or cleanliness. This extends beyond the limited importance of hygiene; it also plays a major role in the issue of disease and disability that is associated with impurity. (Disease and disability are often closely related for example in the case of leprosy). Research indicates that religious leaders deliberately build a bridge

between ancient religious tradition and modern medical knowledge.¹³ In Islam this especially concerns rules about physical purity. All Muslim religious practices are preceded by a ritual cleansing. In addition to physical impurity there can also be spiritual impurity. This spiritual impurity can be broken by speaking out the religiously defined intention of the ritual, before performing any religious cleansing.

Hinduism

In *Hinduism* disability is mainly seen as a result of the wrath of fate, i.e. punishment for sins committed in a past life.¹⁴ Living with disabilities is often seen as paying the penalty for sins and other moral errors. This view serves multiple goals. In the first place the very idea of someone as 'victim of his or her sins' leads to the expression of compassion for these sinners. Pity strengthens charity. Secondly, such a perception makes it easier to distance oneself from one's responsibility: a disabled person suffers 'bad karma' and therefore poverty needs to be undergone patiently, otherwise it will be even worse in a next life.

Like in Islam, Hinduism purity plays an important role, although the concept of purity has a different meaning. In Hinduism it particularly aims at the hierarchy in the caste system, formulated on the basis of cleanliness. This hierarchy is defined in terms of purity and play a role when getting married, sharing of food, performing jobs and in human relationships. This distinction based on purity creates a division between the different castes, but also a mutual dependence on each other. Even though in India the caste system has been outlawed, it continues to play a determining role in society

3.3 Ambivalence

As shown above, on one hand religious traditions (including Christianity, see next chapter) often contain elements that can strengthen a negative or at least passive attitude towards disease and disability. On the other hand we can also find resistance against this negative image and attitude. In religious traditions, resource guidelines for emancipation/liberation are found. Religious communities are excellent places for explicit reflection on what a just society would look like, and how justice can be done to the full humanity of all people. Here we can see starting points to use religion to promote a better relationship between people with and without obvious disabilities. Moreover, religion always has an inside, an experiential side. An individual's own religious experience has an important role to play in a positive way to shape a life with disabilities. This personal religious experience can significantly differ from conventional images of disease and disability in that religion. It is therefore important to take into consideration both the institutional and the personal dimensions of the relationship between religion and disability.

¹³ Modderkolk, Linda (2006), *The people will make distance; een onderzoek naar felt stigma bij mensen met lepra in Noord-India*. Groningen: Rijksuniversiteit.

¹⁴ Ghai, A. (2002). Disability In The Indian Context: Post-Colonial Perspectives. In M. Corker & T. Shakespeare (Eds.), *Disability/Postmodernity: Embodying Disability Theory* (pp. 88–100). London: Continuum.

Chapter 4 Christian view on people with a disability

In this chapter we discuss the relation between Christianity and disability. We dedicate relatively more space to Christianity since Prisma is an association of Christian organisations that find their inspiration and normative view in the Bible. Before presenting a normative Christian view on disability we make some historical remarks.

4.1 Historical remarks

As in the case of other religions (see 3.3), the history of *Christianity* harbours theological sources that contribute to the ‘theological disablement’ of people with disabilities, particularly those with epilepsy.¹⁵ Marginalisation, the process of ‘scapegoating’ and sometimes demonization of people who have disabilities have been practiced in the history of Christianity. In some traditions the blame for suffering is placed upon the sufferer of an illness or a disability. This is considered a desire of God because of the sinfulness of the person who is seen as ‘possessed’ by an evil spirit or demon, and in need of ‘exorcism’ and deliverance. Practice and ideal have often been far apart. At the same time, inspiring examples of care for vulnerable people can be found in the history of the church. It can be safely stated that today’s facilities in Western countries for people with a disability are at least partly rooted in the Christian tradition.

We will now look at the teachings of the Bible on people with a disability.

4.2 Value of human life

Every human being is created in the image of God and to the glory of God. The uniqueness of every human being is revealed in their different qualities. These different qualities, however, do not lead to differences in dignity. Like anybody else, people with a disability are created in the image of God. We should not only accept the people with fewer gifts or a weaker body, but we need them too. Society cannot function well without them because they belong to the whole. They are, as much as anybody else, to be ‘one of us’, created in His image. Everyone is created with a variety of gifts and talents. People with a disability often have low expectations of what they can do or contribute to others, or have (had) less opportunities to develop their talents.

People with a disability often need specific help from others. But at the same time every one else needs other people. We are not created to live in isolated independence, but to support each other and offer help in relationships. To need help is not a sin but is part of human existence that is characterized by mutual dependence and care.

The principle of human dignity and equality causes both positive and negative obligations. Negative obligations in the sense of limits in the way we can treat other people. These obligations express respect for the integrity of the individual and require that we refrain from actions that may hurt or offend others. On the other hand positive obligations require that we act in the interest of other people and actively protect their well-being and rights. Justice and solidarity are elements of ethics that want to guarantee values such as love, respect and reciprocity.

¹⁵ Ray, Joanna Z. (2006) *Practical Theology: in search of the ‘Disabled’ God*. Lulu.

Often people with disabilities are adopted into charity projects. However as a creation of God with gifts and talents we want to approach this group as people with capacities to be used, rather than as being totally dependent on the charity interventions of others.

4.3 Biblical notions on disability/disease¹⁶

4.3.1 Link between sin and sickness

In the Old Testament, sickness and other problems are often seen as a punishment for sin. There is a direct link.¹⁷ Blessing is connected to keeping Gods commandments and listening to his voice, and curse is connected to disobedience to the Lord.¹⁸ The New Testament reveals that we must be cautious to consider personal sin as the cause of disability.¹⁹ We must, therefore, oppose the stigma and discrimination against people with a physical limitation caused by the usual terminology of sin and punishment. Living with a disability, is one of the many ways in which human beings deviate from God and the subsequent brokenness and misery of human life manifests itself. That fundamental brokenness applies equally to all people, and in a fundamental way all human beings are impaired in the sight of God, even though this is more visible for one person than for the other. Hence, although we cannot speak of a direct link between sin and disabilities in an individual life, there is a collective link.

4.3.2 Gods law

In His laws (Torah) to Israel, God demanded protection of vulnerable people in the repeatedly recurring command to care for foreigners, for orphans, for widows, in other words for vulnerable groups in society. For example, in Lev. 19:14 it is written that we should not harm these people by abuse of their limitation.

At the same time there are clear commandments on certain tasks that could only be performed by healthy people, people with no 'infirmity'. Leviticus 21:18 and continuation: 'nobody with any defect may be appointed as priest: no one who is blind or paralyzed, no one with a deformed face or abnormally developed limbs, (...)'. Holy matters should not be desecrated and were protected against impurity. Impurity includes infectious diseases such as leprosy. This was the case in Old Testament times to convince the people of the holiness of God as the God of life in a time in which disease and handicap was seen as a forebode of death.

Jesus summarized the laws of Moses as follows: "Love the Lord, your God, with all your heart and all your soul and all your mind. This is the greatest and first commandment. The second is equal: love thy neighbour as thyself". And Jesus in disobedience to the law of Moses, touched the person with leprosy; but instead of Him becoming unclean, His purity cleansed that person.

4.3.3 Promises fulfilled

In the book of Psalms and in the prophets, we find many promises regarding the temporality of disabilities and defects. Psalm 146:8: 'The LORD gives sight to the blind,

¹⁶ Some of these notions originate from: Chris Sugden (ed.) (1998), *Biblical and theological reflections on disability*, In: *Transformation*, 1998, 15:4, p. 27-30. For more on this subject see also Lausanne Committee for World Evangelization (2004), *How does God view people with disabilities?* In: *Hidden and forgotten people; ministry among people with disabilities*. Lausanne Occasional Paper No. 35B. http://www.lausanne.org/documents/2004forum/LOP35B_IG6B.pdf

¹⁷ An example is Deuteronomy 28:58-61.

¹⁸ Compare for example Deuteronomy 15:4-6.

¹⁹ In sections like for example John 9:1-3 and Luke 13:1-5.

the LORD lifts up those who are bowed down, the LORD loves the righteous.' Jeremiah 31:8: 'See, I will bring them from the land of the north and gather them from the ends of the earth. Among them will be the blind and the lame, expectant mothers and women in labour; a great throng will return.' Isaiah 35:6: 'Then will the lame leap like a deer, and the mute tongue shout for joy. Water will gush forth in the wilderness and streams in the desert.' This again shows that people with disabilities fully belong to the community.

In Luke 4 Jesus is reading from the book of the prophet Isaiah in the synagogue. Luke relates: 'and he began by saying to them, "Today this scripture is fulfilled in your hearing."' (verse 21). In the gospels we see this actually happen: 'Great crowds came to him, bringing the lame, the blind, the crippled, the mute and many others, and laid them at his feet; and he healed them. The people were amazed when they saw the mute speaking, the crippled made well, the lame walking and the blind seeing. And they praised the God of Israel.' (Matthew 15:30-31).

In different ways Jesus shows God's attitude towards people with disabilities²⁰:

- Jesus himself is willing to empty himself of his glory (Phil. 2) to share our limitations and to be open to all those problems and struggles to which human beings are vulnerable.
- He became part of the community of people with disabilities, eating, befriending, teaching and drawing them into the circle of his followers. He cut across the social norms of his day by putting people considered as outcasts at the heart of the kingdom of God.
- Jesus healed people as a sign of hope for all, but also as an act of renewal and transformation. God will make all things new. By healing people he restored them to family and community. He also restored them to shalom, that wholeness which speaks of the kingdom of God.

4.3.4 Wholeness in brokenness

Brokenness-wholeness

We are all created in God's image, one person not more than the other person. Although God's creation was originally good, we live in a fallen and broken world. Everyone's body and soul is subject to disease, decay and ultimately death. Therefore, the equality of all people is a matter of principle. However, those living with an apparent impairment or disability are those most affected by discrimination. From a principal point of view the differences in the manifestation of everybody's brokenness are gradual. But this does not deny that in the experience of people the differences can be quite significant. Deuteronomy 15:10 clearly states that we must provide for the poor, because the poor will never lack in the country. That is why 'I command you to be open-handed toward your brothers and toward the poor and needy in your land' (verse 11). It is clearly indicated that this is not an ideal situation and it is not the normal situation. This is reflected in the New Testament when Jesus refers to physical impairments as metaphors that indicate that people do not want to understand what He says.²¹

Jesus healed people. All healing is a beginning of the biblical concept of 'shalom', life in the kingdom of God which is characterized by wholeness in relationship with God, other people and creation. People with a disability do belong to the community, which is explicitly outlined in Luke 14 where the poor, blind, lame and the paralysed are invited for the big feast. The house of the master should be full.

²⁰ Chris Sugden (ed.) (1998), Biblical and theological reflections on disability, In: *Transformation*, 1998, 15:4, p. 28.

²¹ Matthew 13:13 'This is why I speak to them in parables: Though seeing, they do not see; though hearing, they do not hear or understand.'

Eschatology

People with disabilities are not created in God's image *despite* their disability but *with* their disability. Christians are called to recognize and embrace their weaknesses and find the source of their life in Christ rather than in their own abilities.²² People with disabilities remind the wider community that each person ultimately has strengths and weaknesses. Yet there is hope for the future, the eschatological hope on 'fullness of life'. Eschatology, the Biblical vision of the new earth of which signs can already be seen in our contemporary world. It is the biblical vision in which wholeness and justice become visible. This hope inspires people to not let their final word be suffering, but to continue to search for life in all its fullness.

We do not know what our new bodies will look like or how our bodies will be changed. However, we do know that our human existence will be perfect when we 'will be like Him'.

4.4 The Bible and advocacy for people with a disability

The Bible calls for justice. God's laws and commandments reflect His character and form a standard on how to live. His commandments show the special care for those living at the edge of society. In Deuteronomy, the Israelites were commanded to walk in God's way. This includes that 'He defends the cause of the fatherless and the widow, and loves the foreigners residing among you, giving them food and clothing.'²³

Furthermore, we can think of texts from Isaiah,²⁴ the Psalms²⁵ and Proverbs.²⁶ Or, as summarized in Micah 6:8: 'He has shown all you people what is good. And what does the LORD require of you? To act justly and to love mercy and to walk humbly with your God.' Other important Old Testament scriptures that show God's desire for justice and mercy for his people are Leviticus 25 and Amos 5:11-15.

Justice and care for the poor (and people with a disability are often among the poor) are also seen in the New Testament. Jesus shows this in his actions. He teaches us that the most important commandment is to love God and our neighbour. Love God with all our heart means that we are being changed to be more like Him and to have His heart. Jesus uses the parable of the Good Samaritan to show what this love means in practice (Luke 10:25-37). James teaches Christians to treat all people equally and in particular to not mock the poor or ignore their needs (James 2:1-26).

We can therefore safely say that advocacy is a biblical mandate: to give a voice to those who have no voice and to those whose voice is not heard.

Put in today's language of human rights, which *can* be seen as embodiments of biblical values, we can say that all human beings equally share in human dignity. Hence, being human should give sufficient reason to be treated with dignity. We have to fight for recognition of dignity for every person, whatever his or her situation.

²² 1 Corinthians 1:26-31.

²³ Deuteronomy 10:18, cf. also Deuteronomy 24:17-22 about the rights of the foreigner, the orphan, the widow.

²⁴ Isaiah 1:17 'Seek justice' and Isaiah 58:6-12.

²⁵ Psalm 82: 3-4: 'Defend the weak and the fatherless; uphold the cause of the poor and the oppressed. Rescue the weak and the needy; deliver them from the hand of the wicked.'

²⁶ Proverbs 29:7: 'The righteous care about justice for the poor, but the wicked have no such concern.'

4.5 Actors and their responsibilities

Because people (also people with disabilities) are unique human beings with qualities and capacities, all forms of care and support need to optimally take into account this individuality. In answer to the question “Who is responsible for the support and care that people with a disability need?” we want to distinguish four main circles of responsibility:

- people with disabilities themselves,
- the family,
- the church, and
- the government/state.

4.5.1 People with disabilities

People with disabilities are valuable members of society who can make rich contributions if given the opportunity. People with disabilities can play an active role in organizing the support needed. Some will pro-actively do this, others need to be stimulated or educated in order to be able to do so.

People with disabilities often have the idea that their disability is a reason for not being held fully accountable for their responsibilities. Other important people like family members or other care givers are therefore responsible to stimulate people with disabilities to take responsibility for their decisions, as much as possible according to their abilities. Levels of responsibilities need to be adapted to a person’s physical or mental limitations, but if done it will be a great stimulus for people to be held accountable/responsible.

4.5.2 The family and wider community

When taking into consideration the impact on families, the lives and livelihood of many people are impacted by disability. The impact of having a family member with a disability will vary per situation, depending on the nature of the disability, the resilience of family members or care takers, the personality development of a child’s brothers and sisters and on external support. One’s social position within the environment also plays a role. A family which includes a family member with disability often becomes a ‘family with disability’, with the corresponding insecurity and tensions.

Parents are responsible to take care of their children. Families can make a huge difference in the lives of people with disabilities. It is the parents who decide to stimulate their children to go to school, participate in chores in the household, to take them for medical care and/or rehabilitation. Families are fully involved and play an active leading role in the integration of people with disabilities in society. Reasons why care in the family can be insufficient are often due to lack of knowledge, capacities and opportunities. Lack of care within the family can also be due to perceived stigma and discrimination. Furthermore, in practice families often take the majority of the care because in their situation social services are nonexistent or lack budget.

It is therefore important that families have some sort of social and psychological support, not only in the early stages, but especially when families have to make important decisions. It is of great importance that families with a disabled member have the chance to meet, to exchange experiences and to obtain new enthusiasm in dealing with everyday situations. Organisations of people with a disability and their relatives, often fulfil an important role in this respect. Information channels need to be created to help families to

take up their responsibilities. In this respect caring organisations and their professionals can be of great help. Experts can also help families to achieve a better way of living in acceptance of the disability.

4.5.3 The church

Not only the family and wider society, but also the church and its members have a responsibility in care taking: 'Carry each other's burdens, and in this way you will fulfil the law of Christ.' (Galatians 6:2). Within the church people with disabilities have a position as indicated in the message of 1 Corinthians 12:18, 22.²⁷ The church is *the* place where people should be able to live with each other in love and to value each other. In the church we recognize that in the eyes of God we are all 'disabled'; none of us meets the standards of God. The message of forgiveness and restoration pertains to all of us, calling us to serve Christ and our neighbours with the talents and gifts that He gives each member of Christ's body, the church. Hence, the church especially must be the place where the full humanity of all of its members -and in fact of all people- is affirmed unreservedly. Inclusion of everyone in the Christian community is the work of the Holy Spirit. The Holy Spirit can strengthen people with a disability who believe in Him, giving them talents aimed at becoming more like Jesus. In this process, restrictions can be lifted from them, but more often we see that people learn to reach beyond their limitation: achieve special performance within the limits of their disability or give meaning to their lives and that of others, despite, and sometimes because of, their restrictions. All members of the congregation, whether their restrictions are more visible or less visible, have been called to serve the Lord together, in a community where grief, struggle and joy are experienced. Of course the practice of religious life is always more unruly than the ideal. Yet the gospel offers a basis for the congregation to break down barriers and to seek ways to allow optimal functioning for people with disabilities. By doing so, the congregation is witnessing the love of God and this love also manifests itself practically.

The worship services of the congregation offer an opportunity for an encounter with God. In this encounter differences between people seem insignificant. Jean Vanier²⁸ says about the function of the community: "For each person, for each community it is important to know how someone can stay rooted in his faith, in his identity and his own community while at the same time can grow, give life to others and also receive life from others".²⁹ He refers to the fact that God's work is not independent, but that it will receive full effect in the practical life of the community. Only in this way the community can be a place where people can really grow in and with their situation.

Noordmans sees the time of the community as a time in the *conjunctivus*³⁰: a time that is longing for completion. This is the desire for fulfilment of God's work of salvation.

God in his mercy sometimes heals today, and the church is called to pray for healing.³¹ At the same time, an over-emphasis on healing, and poor practice in this area has caused a great deal of suffering for people living with disability, as well as led people to passive

²⁷ 1 Corinthians 12:18: 'But in fact God has placed the parts in the body, every one of them, just as he wanted them to be.' And 1 Corinthians 12:22: 'On the contrary, those parts of the body that seem to be weaker are indispensable'.

²⁸ Jean Vanier, born in 1928, set up the first Ark community in Trosly-Breuil (France) and lived there with to mentally disabled adults.

²⁹ J. Vanier (1994), In broosheid dragen. Gemeenschap beleven vanuit de spiritualiteit van de ark, Averbode, p.14.

³⁰ O. Noordmans, *Herscheping*, in ID., *Verzamelde Werken*, part 2, p. 315.

³¹ James 5:14-16.

waiting, rather than getting on and doing what God has already equipped them to do in his service.

The idea of inclusion within the church means that people with disabilities have talents that can be used within their church community. People living with disability are needed in the church, and have the responsibility to serve, care for and minister to others. People with disabilities are being involved in the same way as others by taking both their talents and their limitations seriously. They do not need exceptional positions. Within the community we should look at everybody and assess what is needed within the community and what can each individual person offer?

Within the church attention is needed for the idea of total communication: how to 'tell' the Gospel to people with a (mental) disability? This can be done in an interactive way, with drama / mime, many visualizations (e.g. with pictures or objects), adapted services, using simple examples or explanations, adapted home visits / Bible studies / catechism lessons or have people with disabilities help in preparations for the service. It should not be difficult to think of many different activities or methods. However, we should always start by getting to know the people implied. What applies to a certain person? Starting point is trying to get into someone's life world, understanding his or her world. As far as possible we should ask people with a disability themselves, what ministry he or she would be willing to take up. Each congregation is different; every person with a disability is different. The congregation is called to be a living community, actively seeking for a good place for everyone.

4.5.4 The government

Governments are responsible to protect, maintain, promote, respect and exercise human rights, including the rights of people with a disability. Examples of these obligations of a government are to provide good health care, including all means necessary to support people with a disability (wheelchairs, adaptation of housing, etc.), and to make sure – if necessary with legislation - that the disabled can (re)integrate into society and participate in economic activities, etc. Often, however, political will, knowledge and determination to take measures that will enable this group to get to know and to practice the rights they have based on various other international treaties, is lacking.

Development cooperation also needs a rights-based approach that explicitly takes into account the rights of people with disabilities. This will meet their basic needs, but implies particularly that they become aware of the laws and regulations (national and international) that can protect them to exercise their rights. Exercising their rights allows opportunities and choices to improve, and it also helps people with disabilities to take responsibility. This means that in the first place it is essential to strengthen, organize and mobilize people with a disability and their interests, so that they get more (decision taking) influence on events and situations that affect their lives (empowerment). Development cooperation can contribute to this process of change both by helping to provide the required support and services, and by continuously asking attention and support for the protection, maintenance, respect and exercising of the rights of this group. Publications of DFID and Danida demonstrate this as well³².

The Convention on the rights of persons with disabilities in Article 32, endorses the importance of international cooperation in promoting that the rights of persons with a disability can actually be exercised. By signing, and then ratifying the treaty, States

³² See for example <http://www.dfid.gov.uk/Documents/diversity/disability-core-script.pdf>

commit themselves to enact laws and other measures, to improve disability rights, as well as abolish discriminatory legislation, customs and practices.

4.5.5 Other stakeholders

Donors should individually and jointly insist on the improvement of the socio-economic circumstances of people with disabilities. So far, across various donors, this is happening insufficiently. Addressing the position of people with a disability with the government, means that organizations in development cooperation need to be able to show their efforts in this area. Several member organizations of Prisma have already been reflecting for some time on how to make their programs more inclusive. Some relatively simple measures could be:

1. A certain percentage of spending within the health care program is designated to disability mainstreaming. This can be used to make a program accessible to people with disabilities, such as training for staff (dealing with people with disabilities, simple sign language), access to facilities for wheelchairs, adjusting education materials for people with learning difficulties, awareness raising in the communities. This benefits both people with a disability as well as other vulnerable groups.
2. The organization looks locally for opportunities to cooperate on this issue with public organizations, like professional caring organisations, or other civil society organizations such as Disabled People's Organizations (DPOs). The organisation also investigates what facilities already exist.
3. In HIV and AIDS programs an effort is made to look for opportunities to reach people with disabilities, e.g. by adaptation of information (Braille, audio and video materials).
4. In the project evaluation and in communication with the partner organization, in addition to mainstreaming of gender and HIV & AIDS, mainstreaming of disability can be taken into account in order to measure whether goals have been achieved.
5. People with disabilities participate in designing, implementing and evaluating projects and programs.
6. It is important to not only focus on this specific target group, but to also take into account the needs of other stakeholders, especially the family.

Chapter 5 Policy directions

5.1 Twin track approach

Based on their respective missions, Prisma members support the rights of the vulnerable. Prisma sees both reasons and opportunities for a policy shift in this area. Following DCDD, Prisma recommends a twin track approach or strategy. Measures that will specifically target people with disabilities through health, rehabilitation and education/training programs, and measures that will work to mainstream disability issues in sector programs. In other words: specific where needed and inclusive where possible. Formulation of policy should take place with the participation and substantial contribution of people with disabilities themselves: 'Nothing about us, without us.'

In order to improve the position and situation of people with disabilities, policies are needed in developing countries that address these groups of people systematically and in all relevant areas. Increasingly, developing countries are adopting Disability Laws that stress equality and inclusion. However, implementation of such policies remains a challenge.³³ In addition to such mainstreaming of disability (in all kinds of social contexts), specific services for people with disabilities continue to be of substantial importance for those groups of people. Prisma supports both strategies as complementary approaches. Since mainstreaming of disability can create opportunities to include people with a disability, for organisations working with integrated development programmes, in this chapter we want to specifically pay attention to mainstreaming.

Awareness raising and community empowerment are a third, very important element. In order for people with disabilities to be able to fully participate in society and be considered as equal citizens, societies have to be aware and open. They need to be open to change their attitudes where needed, and to accommodate (facilitate) all groups.

5.2 Introduction to mainstreaming

5.2.1 Definition

In order to reach a substantial proportion of people with a disability, and really take a leap forward in achieving the Millennium Development Goals (MDGs), we will need a process of mainstreaming of disability. This mainstreaming is even in addition to the existence of more specific actions and services for specific groups of people.

'Mainstreaming disability into development cooperation is the process of assessing the implications for disabled people of any planned action, including legislation, policies and programmes, in all areas and at all levels. It is a strategy for making disabled people's concerns and experiences an integral dimension of the design, implementation, monitoring and evaluation of policies and programmes in all political, economic and societal spheres so that disabled people benefit equally and inequality is not perpetuated. The ultimate goal is to achieve disability equality.'³⁴

³³ Mwendwa et al. (2009), Mainstreaming the Rights of Persons with Disabilities in National Development Frameworks, *Journal of International Development* 21, pp. 662-672.

³⁴ Department for International Development (DfID) (2000), *Lessons from the disability knowledge and research programme* (www.disabilitykar.net/learningpublication/contents.html)

Mainstreaming of disability is therefore essential to prevent the exclusion of people with a disability, from sharing in political, economical and social activities in society.

5.2.2 Preconditions

When asked why people with disabilities were not involved in the offered programs or services, usually partner organisations offer one of three explanations. These are: disability is a specialist issue, there are no people with a disability in the community, and programs are open to people with a disability but they choose not to come.³⁵

Prisma member organisations mention about the same reasons, although in a slightly different tone. They include:

- a) There are too many different requirements for partner organisations. Why mainstreaming of disability should be added in the programmes is an issue; concerns arise that it will replace issues just as important like mainstreaming of gender and/or HIV and AIDS, a process which has not yet been completed. It can become a difficult consideration between interests of different vulnerable groups. The question is, who will decide what are the priorities?
- b) Mainstreaming might eventually lead to less attention for the target group at stake. It can be argued that mainstreaming is not the right method, or that by mainstreaming the attention for disability will slowly disappear (like it did with e.g. gender activities).
- c) Organisational requirements. It needs to become clear what the preconditions are for starting with mainstreaming: steps to take, how much money will be involved, what support is needed from partner organisations.

These issues need to be addressed at an organisational level. Mainstreaming disability is not a requirement for Prisma programmes but a recommended direction (see also paragraph 5.1 about the twin track approach). As said earlier, Prisma adheres to the twin track approach, but not every organization should be involved in both tracks. However, Prisma would argue in favour of the implementation of both tracks in all programmes. Individual organisations may choose not to be involved in mainstreaming disability –at least for the moment. Context analysis and other stakeholders are taken into consideration. Sometimes it may be considered better to hand over to other stakeholders as specific interventions are required. Mainstreaming should never be an aim in itself but must be considered as a worthwhile challenge. To explore this direction, a pilot project will be started in the Prisma network on mainstreaming disability.

Good knowledge of local situation

If we want to mainstream disability in a specific project it is necessary to be aware of the particulars of the local situation. A context analysis is required. Not everyone within a community has the same knowledge about this subject or is open enough to reflect on mainstreaming. People with disabilities themselves or their family might be good reference persons, and it is of great interest to have them participate in this exploratory phase. In addition the community as a whole needs to be aware of the importance of the inclusion of people with disabilities.

Training and capacity building

³⁵ Micah Network Asia-Pacific Regional Forum (2007), *Plenary paper on disability and marginalisation*.

Although disability is clearly visible in communities, only a small number of NGO staff is familiar with this phenomenon. It is necessary to understand how disability affects opportunities for individual development, development of the family and of the community to which that person with a disability belongs. Finally the regional and national interest of equal opportunities for persons with a disability is an important consideration. It would be good if staff of NGOs would attend a basic training on:

- Factors that increase vulnerability to disability.
- The increasing role of poverty in both the appearance and the consequences of disability.
- The link between disability and gender.
- Other social influences that prevent, promote or cause disability.
- The importance of mainstreaming at activity level.

Attitude of staff

For the process of mainstreaming, it is important that the entire staff of the organization stands behind it. In many cases this requires a change of attitude that needs time. Someone in a key position needs to first introduce the subject to the whole organization. The positive result of an internal lobby is dependent on three levels:

- Identification: key people within the organization recognize the importance of disability in relation to underdevelopment and poverty.
- Conviction of importance: others see the importance of this issue for the work of their organization.
- Ready for action: key people recognize mainstreaming of disability as an active way to work on this topic and are ready to get started practically .

In addition to this process of awareness raising, there are two other important conditions: financial resources and human resources (commitment). Financial resources are needed to support the process of mainstreaming, for example a budget monitoring training. Commitment of staff is required to take responsibility for initiatives. It would be good to have one or two people in the organization who can stimulate and support the process.

5.3 Mainstreaming in practice

5.3.1 Introduction

As mentioned earlier, it is recommended for development organisations to pay attention to disability in their own workplace policies, in programs and in other policies (mainstreaming). At these three levels, we need to examine:

- The possible effects of plans on the position of people with disabilities.
- How people with disabilities can participate fully in activities and projects, and in the designing of these activities (inclusive thinking).

Thinking about the mainstreaming of disability, requires active participation of people with a disability in making inclusive work and office, programs and policies.

5.3.2 Workplace policy

Workplace policy concerns their own staff and office. The staff can be assisted in becoming aware of barriers that people with disabilities experience in the workplace, of discrimination and exclusion. In the workplace, any agency can pay attention to, for example, accessibility of the office, appropriateness of physical work places for employees with disabilities, making available positions in the organisation and in the board for people with disabilities. Much knowledge is available in Dutch organizations of

persons with disabilities: platforms like Handicap and Society, Handicapenwerk.nl, CG-board and so on. A useful tool is: 'A Handbook on Mainstreaming Disability of VSO (2006)³⁶. This book gives many practical references.

5.3.3 Programs and policy

Attention in programs and policy concerns the relationship with partner organizations. This doesn't mean primarily new programs and new activities, but focuses on the introduction of disability as a crosscutting issue. Parts of this practice and rationale can be captured in programs and policies.

There are specialized international NGOs in the field of disability and development cooperation who have much knowledge in the field of inclusive programs and policies. A few of them are Handicap International, CBM International, Dutch Coalition on Disability and Development (DCDD) and International Disability and Development Consortium (IDDC). Within Prisma and the ICCO Alliance, The Leprosy Mission and Dark & Light Blind Care are specialized organizations. Also at the Prisma office necessary knowledge can be obtained.

The next step is to identify in which projects and programs important progress can be made, by making them inclusive and by involving people with disabilities in planning inclusive projects and programs. A useful document on this topic is: 'Disability and Development; experiences in Inclusive Practices', issued by CMB and Handicap International (2006)³⁷. The Handbook of VSO also gives much information. DCDD is happy to advise on ways in which disability can be included in policy.

The way that measures which contribute to the mainstreaming of disability can be embedded in projects and in the procedures of the organization, depend on the type of activity and the local context. Some possibilities include to:

- Pay attention to the mainstreaming of disability in the job descriptions of staff, in evaluation mechanisms and in the vision and mission of the organization.
- Ensure standard procedures on non-discriminatory behaviour towards people with disability.
- Determine what measures could be considered in cases which employees demonstrate discrimination.
- Work on practical action for mainstreaming of disability in every phase of the project cycle.

5.4 Methods of mainstreaming in specific sectors

There are a number of sectors in which it is particularly important and also possible to give people with disabilities access to, and strengthen the position of people with disabilities, in program and project design.

Education

In developing countries, the basic and secondary education of people with disabilities often rely on special needs schools. These schools have the disadvantage that only a

³⁶ http://www.asksource.info/pdf/33903_vsomainstreamingdisability_2006.pdf

³⁷ <http://www.handicap-international.fr/fileadmin/documents/publications/DisabilityInDevelopment.pdf>

small proportion of children with disabilities are able to attend these schools: they are expensive and it usually requires the child to be away from the family, staying in a school residence. After finishing their education it is often difficult to get back to their family. The family and community often consider people with disabilities as unable to learn and work, not seeing the growth of the child. Inclusive or integrated education is cheaper and can reach many more children. They can stay with their families, are visible in their own community, and mix with other children. In this way they can be a natural part of the community where they can be recognized and valued. This is contrary to what we often think is possible of inclusive education particularly in developing countries. With additional training for teachers and external support to the school, many more children with disabilities can go to school. It also provides them with greater chances to generate their own income after they have finished their education. Education for All as the elimination of extreme poverty comes a lot closer. Many materials can be found on the Internet.³⁸

Vocational training

Vocational training is a model frequently used to give people opportunities to cope with situations of extreme poverty. Until today it is rare for people with disabilities to be part of programs for vocational training. Making these programs as inclusive is possible, when the will is there. In principle, the training should focus on 'ordinary' market-oriented work and not on protected forms of work. The latter form of work should only be considered for lack of other options. Barriers, that hinder people with a disability to take part in regular vocational training programmes, can be cost, awareness of trainers, accessibility of training centres, transport, preparatory training, communication during the training (i.e. for hearing and sight impaired) and lack of information. In many cases, these causes can be addressed properly. Much material on vocational training and employment for people with disabilities can be found with the ILO. Dark & Light has made a handy overview of all aspects, with source citations, including practical methods to integrate people with disabilities who are successfully in employment and vocational training, such as community based rehabilitation.³⁹

Savings, credit and market support

People with disabilities are rarely part of projects for (micro)credits, formation of production groups, marketing and support to access the labour market. This has to do with lack of knowledge, prejudice and lack of adjustments in the workplace.

Health

People with disabilities often face various barriers that hinder access to health care at all levels. There are physical barriers such as stairs and thresholds. In most sectors of health care people with disabilities are often not taken into account. For instance, people with disabilities are regarded as not having sexual intercourse or desire to have it; hence information and services are not addressed to them; health education materials are poorly accessible to the blind, the deaf and people who are illiterate; danger of abuse by health professionals is higher for those with disabilities than for people without. Many obstacles are due to unfamiliarity of health professionals with disabilities, prejudices, lack

³⁸ Cf. the overview made by Dark&Light blind Care:

http://www.darkandlight.org/Uploaded_files/Zelf/InternationalexperiencesInclusiveEducation1210318134.pdf

³⁹ www.darkandlight.org/Uploaded_files/Zelf/International%20experiences%20Vocational%20Training%20and%20Income.pdf

of communication skills or willingness to communicate with people with certain restrictions. Equipment is not always suitable for everyone, such as an examination table not being height adjustable. Prevention of disability is often possible through integration into basic health care.

HIV and AIDS

Research has shown that people with disabilities are at a higher risk of infection with HIV and AIDS than people without disabilities: information is poorly accessible, people with disabilities are more likely to be abused (especially women and children). Services are usually not adjusted (see health), putting people with disabilities in a disadvantageous position.

Community development

Inviting people with disabilities to take part in community development, for example by participating on village committees, will help to include their perspective for an inclusive development plan. Also the support of disabled people's organizations increases their involvement in various development processes.

See also 'Questions for mainstreaming disability in projects' in annex 1. Another useful tool is the checklist for inclusion by USAID: www.usaid.gov/gt/docs/miusa_checklist.pdf.

At a later stage it would be good to compare this chapter to the new CBR guidelines of the WHO which are being developed and will be available at the end of 2010. Mainstreaming in all social and cultural spheres of life will be discussed. Considerations should be made per sector for what can be done to facilitate mainstreaming.

Annex 1 Questions for mainstreaming disability in projects

Source: Platform Handicap en Ontwikkelingssamenwerking (2005), *Mainstreaming disability and HIV/AIDS; a double challenge*. Brussels: P.H.O.S.

People with disabilities, themselves, or their relatives, may be good contact persons and must, in every case, be involved in the exploration of the mainstreaming process. It is possible that, because of the taboo, these people are difficult to reach. An efficient, but time consuming method would be to try to establish personal contact with families by going from door to door in order to informally collect information on the following aspects:

- Behaviours towards men, women, adolescents and children with disabilities and/or HIV/AIDS
- The proportion of households with individuals with disability and/or HIV/AIDS
- The effects of disability and/or HIV/AIDS in the different kinds of households, on individual members of the family and on food provision
- The impact of disability and/or HIV/AIDS on the household and the community levels
- The changes in behaviour of the larger community towards men, women and children with disabilities and/or HIV/AIDS

We must also have an idea about the experiences of men, women, and children with disabilities and/or HIV/AIDS:

- How do they experience the evolution of their disabilities and/or disease?
- According to them, what is the impact of their disability and/or disease on themselves and on the different members of their household?
- What do they consider as being the cause of their disability and/or disease?
- What are their conceptions of how to prevent disability and/or HIV/AIDS?

We do not get answers to such questions in only one home visit. Therefore, it is advised to set up discussion groups through participative methods. For the formation of the different discussion groups, it could be suitable to use already existing informal groups or organizations of persons with disabilities or HIV/AIDS. However, because of the stigma and of the practical difficulties people with disabilities and/or HIV/AIDS have to cope with, in order to get organized, such groups generally do not exist and must be created.

Because of the sensitivity of themes like disability and/or HIV/AIDS, we must pay attention to the following aspects:

- Are all disabilities present in the communities represented in the discussion group? Are people at different stages of HIV/AIDS represented?
- Is there a balance in the number of men and women, the division by age groups, and the social positions in the community?
- Who are the main figures in the group and how can we guarantee that the opinion of the others will also be considered?
- It would be good if the facilitator asked the participants, what they would like to see happening at the beginning of the discussion. At the end it is important to check whether everyone is satisfied. A good way to do this is by asking the following question: "What have I failed to bring up that is important to you about this issue?"

It may be interesting to complete the group discussions by only a few individual interviews, in order to consider personal aspects that people do not want to talk about with the group.

If we want to work on disability as well as on HIV/AIDS, it is better to work with two distinct groups, because there are many differences between disability and HIV/AIDS. Moreover, people are generally more open to discussion in groups where everybody lives with more or less the same situation.

It is also advisable to launch a separate discussion group with key figures in the community, as well as with other interested people who are not directly involved in these themes of disability and/or HIV/AIDS. This would involve people who are not themselves, nor through their families, directly affected by disabilities and/or AIDS. It is possible to discuss the following subjects with them:

- How do they behave with people with disabilities and/or HIV/AIDS within their communities?
- What do they know about the prevention of disability and/or HIV/AIDS, and what do they do concretely about it?
- Which do they themselves see as the cause of the different disabilities and/or HIV/AIDS?
- According to them, what is the impact of disability and/or HIV/AIDS on the community?

Here also, it is important to have a balance between men and women, between different ages and between individuals with different social positions. Once we have a global view on the visions and attitudes existing around disability and/or HIV/AIDS among people directly concerned, as well as in the community at large, we can bring the two groups together. In this joint discussion group, the following questions could be raised:

- Do the activities and projects set up by the community take disability into account?
- If yes, how? What does work? What doesn't work? How can these things be improved?
- If no, set up a plan of the steps to be taken towards disability that is supported by everybody, and designate who will take responsibility for what.

Once we have received, via the discussion groups, an initial understanding of the changes to be made and of the community members who should play a role, we must study existing activity and projects in the community, as the way in which general elements of a plan can be implemented. Describe the project with the following questions in mind:

1. Describe the project with the following questions in mind:
 - How do disability and/or HIV/AIDS influence the living conditions of people who are confronted with it?
 - How does that influence their chances to avoid poverty?
 - How does an NGO's work contribute to the prevention of disability and/or HIV/AIDS?
 - How does an NGO's work help people directly concerned and, more generally, the community, to behave differently towards those with disability and/or HIV/AIDS?
2. Reinforce the security net on which households can call by:
 - targeting a general increase in the revenues of the household
 - stimulating savings and the growth of the finances of the families

- avoiding the need for people to sell their means of production, (for example, machines or cattle), in order to buy the food they need.
3. Build or reinforce the security nets at the community level by :
- supporting families in educating and caring for their children
 - bringing food to people or supporting them in their capacity to get food on their own
 - putting other needed resources at their disposal such as clothes and soap.

In all these fields, we must not only pay attention to the most vulnerable and most affected persons, but also to the gender factor, the age factor and to other diversity factors that change the vulnerability towards disability

Annex 2 Bible passages for reflection

Source: Chris Sugden (ed., 1998), *Biblical and theological reflections on disability*, In: Transformation, 1998, 15:4, p. 27-30.

Old Testament

'Do not curse the deaf or put a stumbling block in front of the blind, but fear your God. I am the Lord' (Leviticus 19:14).

'The Lord said to Moses, "Say to Aaron: 'For the generations to come none of your descendants who has a defect may come near to offer the food of his God. No man who has any defect may come near: no man who is blind or lame, disfigured or deformed; no man with a crippled foot or hand, or who is hunchbacked or dwarfed, or who has any eye defect, or who has festering or running sores or damaged testicles. No descendant of Aaron the priest who has any defect is to come near to present the offering made to the Lord by fire. He has a defect; he must not come near to offer the food of his God. He may eat the most holy food of his God, as well as the holy food; yet because of his defect, he must not go near the curtain or approach the altar, and so desecrate my sanctuary. I am the Lord, who makes them holy' " ' (Leviticus 21:16–23).

'For this is what the Lord says: "To the eunuchs who keep my Sabbaths, who choose what pleases me and hold fast to my covenant – to them I will give within my temple and its walls a memorial and a name better than sons and daughters; I will give them an everlasting name that will not be cut off" ' (Isaiah 56:4–5).

New Testament

'One Sabbath, when Jesus went to eat in the house of a prominent Pharisee, he was being carefully watched. There in front of him was a man suffering from dropsy. Jesus asked the Pharisees and experts in the law, "Is it lawful to heal on the Sabbath or not?" But they remained silent. So taking hold of the man, he healed him and sent him away. Then he asked them, "If one of you has a son or an ox that falls into a well on the Sabbath day, will you not immediately pull him out?" And they had nothing to say' (Luke 14:1–6).

'Then Jesus said to his host, "When you give a luncheon or dinner, do not invite your friends, your brothers or relatives, or your rich neighbours; if you do, they may invite you back and so you will be repaid. But when you give a banquet, invite the poor, the crippled, the lame, the blind, and you will be blessed. Although they cannot repay you, you will be repaid at the resurrection of the righteous" ' (Luke 14:12–14).

'There are different kinds of gifts, but the same Spirit' (1 Cor. 12:4).

'Now to each one the manifestation of the Spirit is given for the common good' (1 Cor. 12:7).

'But in fact God has arranged the parts in the body, every one of them, just as he wanted them to be' (1 Cor. 12:18).

'Now you are the body of Christ, and each one of you is a part of it' (1 Cor. 12:27).

'For we are God's workmanship, created in Christ Jesus to do good works, which God prepared in advance for us to do' (Eph. 2:10).

'Is any one of you in trouble? He should pray. Is anyone happy? Let him sing songs of praise. Is any one of you sick? He should call the elders of the church to pray over him and anoint him with oil in the name of the Lord. And the prayer offered in faith will make the sick person well; the Lord will raise him up. If he has sinned, he will be forgiven. Therefore confess your sins to each other and pray for each other so that you may be healed. The prayer of a righteous man is powerful and effective. Elijah was a man just like us. He prayed earnestly that it would not rain, and it did not rain on the land for three and a half years. Again he prayed, and the heavens gave rain, and the earth produced its crops' (James 5:13–18).

'The Word became flesh and made his dwelling among us. We have seen his glory, the glory of the Only Begotten Son who came from the Father, full of grace and truth' (John 1:14).

'He bent over and looked in at the strips of linen lying there but did not go in. Then Simon Peter, who was behind him, arrived and went into the tomb. He saw the strips of linen lying there, as well as the burial cloth that had been around Jesus' head. The cloth was folded up by itself, separate from the linen' (John 20:5–7).

'Jesus said, "Do not hold on to me, for I have not yet returned to the Father. Go instead to my brothers and tell them, 'I am returning to my Father and your Father, to my God and your God'"' (John 20:17).

'On the evening of that first day of the week, when the disciples were together, with the doors locked for fear of the Jews, Jesus came and stood among them and said, "Peace be with you!" After he said this, he showed them his hands and side. The disciples were overjoyed when they saw the Lord' (John 20:19–20).

'Then he said to Thomas, "Put your finger here; see my hands. Reach out your hand and put it into my side. Stop doubting and believe" ' (John 20:27).

'Jesus said to them, "Come and have breakfast." None of the disciples dared ask him, "Who are you?" They knew it was the Lord. Jesus came, took the bread and gave it to them, and did the same with the fish. This was now the third time Jesus appeared to his disciples after he was raised from the dead' (John 21:12–14).

Annex 3 Online discussion groups on disability and the Bible

Micah network e-mail forum

The Micah Network is a coalition of evangelical churches and agencies from around the world committed to integral mission. Convened by this network, 140 leaders of Christian organizations involved with the poor, from 50 countries met in Oxford in September 2001 to listen to God and each other for mutual learning, encouragement and strengthening as they served the cause of the kingdom of God among the poor.

There are some email forums around, one of which is the disability forum. The biggest request was for a forum to discuss the Biblical basis of disability / integral mission related to disability etc. More information:

<http://www.micahnetwork.org/en/learning/forums/disability-forum>

Discussion list European Society for the Study of Theology and Disability

In Europe there is an online discussion list for the European Society for the Study of Theology and Disability (ESSTD-Online), which elicits the interchange of ideas and experiences between those working in Practical Theology and/or those working with people who have disabilities. Link: <http://groups.google.com/group/ESSTD-Online>

This group is not very active.

More about the European Society for the Study of Theology and Disability can be found at <http://www.abdn.ac.uk/cshad/EASDT.htm>

Theological Perspectives on Disability (TDSPex)

TDSPex is a small Dgroup that seeks to explore what the bible has to say about questions of disability and the place of disabled persons in society. Traditionally, Christian attitudes towards persons with a disability has been one of compassion and charity and it is time to re-evaluate that and to see what other perspectives may be adopted.

It offers possibilities to share documents and internet links and facilitates correspondence. This is a group for members only. Link:

http://us.rd.yahoo.com/evt=42879/*http://groups.yahoo.com/group/TDSpex